

Report of the Developmental Disabilities Special Investigative Committee



Senators Steve Lathrop (Chair), John Harms (Vice Chair), Greg Adams,
Abbie Cornett, Tim Gay, Arnie Stuthman and Norm Wallman

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INTRODUCTION

The Developmental Disabilities Special Investigative Committee was established by the Legislature in response to reports from the Department of Justice (DOJ) and the Centers for Medicare and Medicaid Services (CMS) which documented repeated episodes of abuse and neglect of residents at the Beatrice State Developmental Center (BSDC). LR 283, passed by the full Legislature, authorized the Committee to conduct its investigation over the interim and provide a report of its findings by December 15, 2008.

The composition of the Committee was established by the Executive Board of the Legislature which appointed Senators Lathrop, Harms, Gay, Cornett, Stuthman, Adams and Wallman to serve. The Committee has been chaired by Senator Steve Lathrop. Senator John Harms has served as Vice Chair.

LR 283 established the scope of the Committee's undertaking. LR 283 provides in relevant part:

“2. The Developmental Disabilities Special Investigative Committee of the Legislature is hereby authorized to study the quality of care and related staffing issues at the Beatrice State Developmental Center. The Committee shall also investigate the placement and quality of care statewide for the developmentally disabled in Nebraska, including the determination of whether adequate funding and capacity exists for persons to be served in the community, options for service provisions for current residents of the Beatrice State Developmental Center at other 24 hour care facilities in the state, and the staffing practices at 24 hour care facilities and the relationship of those practices to the quality of care provided to the developmentally disabled. The Committee shall also study the Department of Health and Human Services with respect to such facilities, including how and why services to the developmentally disabled were permitted to decline to the level as documented by the United States Department of Justice report.” (LR 283)

The work of the Committee necessarily required not only a study of the difficulties at BSDC, but also a comprehensive study of community based programs and the waiting list for those families wishing to receive services for a loved one with developmental disabilities. To fully discharge its duties, the Committee conducted hearings throughout the interim during which representatives from the Nebraska Department of Health and Human Services (HHS) as well as various experts in the field were invited to speak. In addition, employees at BSDC as well as families with loved ones with developmental disabilities addressed the Committee. In some cases, the testimony related to what Nebraska is doing well and too frequently the testimony related to significant problems not only at BSDC but in alternative programs employed by the State in delivery of services.

The Committee received and reviewed volumes of documents related to the provision of services to individuals with developmental disabilities including studies by the Nebraska Advocacy Services, the Department of Justice and the Centers for Medicare and Medicaid

Services. The Committee also conducted informal, unrecorded interviews with representatives from DOJ and CMS.

The Committee believes that a full understanding of the significance of the problems facing the State of Nebraska as a provider of services to individuals with developmental disabilities necessarily requires a working understanding of the population, the legal requirements relative to the care of individuals with developmental disabilities, as well as an overview of community based programs and the systems in place which are intended to provide oversight of these services.

This Committee has undertaken this investigation mindful of the fact that services for individuals with developmental disabilities are delivered by the Nebraska Department of Health and Human Services which, in turn, is an agency of the executive branch. Our goal is not to embarrass or fingerpoint. However, to discharge its responsibility as a check and balance against the Executive branch, the Legislature must necessarily provide a candid and blunt report on the shortcomings of a system which, for most families, is the only available provider of services to a high needs population.

SPECTRUM OF DISABILITIES WITHIN THE DEVELOPMENTALLY DISABLED POPULATION

The phrase “developmental disability” is a legal term. It denotes a disability that occurred during the first 22 years of life, the majority of which occur around birth or sooner.¹ It is, in practice, a phrase most often used to describe the intellectually impaired whose disabilities range from the very mild to profound. The phrase, however, is broad enough to include those who are “health impaired”. A common example of “health impaired” are those individuals with significant orthopedic limitations. Very often this group of health impaired individuals has no intellectual limitation but, rather, face physical limitations which carry with them mobility and communication challenges.

Frequently those who fall within the phrase “developmentally disabled” carry a dual diagnosis. The dual diagnosis often involves cognitive impairments coupled with behavioral health issues and/or other health issues which limit an individual’s ability to ambulate, see, hear, or speak.

Within each of the classifications of impairments, there is a broad spectrum of limitations. Intellectual impairments can range from mild to profound. The profoundly impaired individuals typically have massive brain damage. This group generally functions at a level such that they are unable to do simple life skills. They will need assistance with the very basic activities of daily living such as hygiene, dressing and feeding themselves. This group requires a great deal of care, most of which is directed toward providing for their needs and maximizing their abilities given their profound intellectual limitations.

A majority of those with intellectual disabilities fall in the moderate range. This group is functional. These individuals generally stay in the school system for 21 years and, with proper care and assistance, can transition into an outside setting.

At the mild end of the spectrum are those with mild deficits. With education and socialization, they become very functional. This is the area in which care providers have experienced the greatest success.

Just as individuals with intellectual impairments fit on a broad spectrum so too do those with health and behavioral disabilities. Health impairments can range from mild problems at one end of the spectrum to those who are medically fragile, including those who take nutrition through a G tube and breathe with the benefit of a tracheotomy. Similarly, their behaviors fall on a wide spectrum. At the mild end are those behaviors which, with simple strategies can be corrected and modified. By contrast, there are, at the other end of the spectrum, those whose behavior presents a significant risk of harm to the individual or those around him.²

¹ Dr. Bruce Buehler testimony, June 23, 2008, page 7.

² Dr. Bruce Buehler testimony, June 23, 2008, page 8

OVERVIEW OF SERVICES IN NEBRASKA FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Care for individuals with developmental disabilities is provided in a variety of forms. In the earliest years of life, most services are provided through a child's school district. Federal law mandates that school districts provide for a child's needs as necessary to educate them to their full potential. The school districts in Nebraska have, according to those who appeared before the Committee, done an excellent job in discharging their responsibilities to young Nebraskans with developmental disabilities. Typically, the services provided by school districts continue to a child's 21st birthday, after which time individuals with developmental disabilities turn to the state for services provided in an array of different settings.

The most comprehensive level of care is provided by Intermediate Care Facilities for the Mentally Retarded (ICF/MR). BSDC is a state-run ICF/MR. In addition to the Beatrice State Developmental Center, there are three privately run ICF/MR's which are operated by Mosaic in the communities of Axtell, Grand Island and Beatrice. ICF/MR's provide a full range of services including medical services and therapy, as well as active treatment.

In addition to its responsibilities as an ICF/MR, the Beatrice State Developmental Center also provides three other programs. The first is the Outreach Treatment Services Program (OTS), the purpose of which is to aid community treatment teams in reducing problematic behaviors and improving the quality of life of individuals who are in community placement. This service typically involves a team from BSDC, such as a psychologist, human services treatment specialist, and psychology intern, observing the individual in a residential vocational community and/or educational setting over a three day period. After a review of the individual's file, and following the observation period, the OTS team will provide the community based provider with strategies for addressing the individual's behavior issues.

The second program offered by the BSDC is the Intensive Treatment Services Program (ITS). The ITS program is designed for individuals with behavioral challenges which require attention in a more secure environment. To accomplish this, BSDC offers 90 to 100 day admissions to its ITS program. The ITS program employs a biopsychological approach to assessment, diagnosis, and behavioral stabilization. Treatment modalities include behavior management, individual counseling, psycho-educational groups, recreational therapy, vocational therapy and opportunities for individualized experiential learning. Upon completion of the program, individuals are typically returned to their community setting with recommendations and a discharge plan formulated to aid in the successful transition from the treatment setting back into the community.

The final program offered by BSDC is the Bridges Program. The Bridges Program is operated by BSDC but is located at the Hastings Regional Center campus. The Program specializes in services to individuals with developmental disabilities designed to provide a structured therapeutic environment for persons with the most challenging behavior who pose significant risk to members of the community. This program has a capacity to serve up to 14

adult males. Typically the Bridges Program is utilized only when all other treatment options and less restrictive environments have failed or are unavailable to meet the needs of the individual.³

The Beatrice State Developmental Center is a unique institution for a number of reasons. The most obvious unique characteristic of BSDC is the fact that it stands alone as the only state-run institution for individuals with developmental disabilities. As an ICF/MR, BSDC serves as a residential facility providing a full spectrum of services typically found in an ICF/MR. BSDC is also unique because, unlike the private ICF/MR's run by Mosaic, it has distinguished itself as the only ICF/MR in the state to have been decertified by CMS and found by the DOJ to have violated the civil rights of those who rely upon this institution for care, treatment and rehabilitative services. As of the date of this report, 250 people call BSDC home.

BSDC also finds itself serving the greatest percentage of the more challenging clients with developmental disabilities. For example, while 50% of the community-based clientele are mildly disabled, only 16% of BSDC's clientele are mildly disabled. Similarly, while 29% of the individuals served in the community fall within the moderate range of disabilities, BSDC's population of moderately disabled is only 11%. Severe disabilities represent 10.6% of the population in the community while 12% of the BSDC population has severe disabilities. Finally, and perhaps most telling, is the disparity found in services provided to individuals with profound developmental disabilities. In a community setting, those with profound disabilities represent only 6.4% while at BSDC they represent 59% of the population.⁴

BSDC also has a disproportionately higher percentage of those with health and behavioral issues. Those with uncontrolled or difficult to control seizure disorder represent 39% of the BSDC population compared to 12% of those in the community. 26% of the population at BSDC have hearing impairments compared to 4.8% in the community. At BSDC 52% of the individuals require a wheelchair for mobility in contrast to less than 10% in the community. Finally, and perhaps most importantly, persons with severe and persistent mental illness in addition to their developmental disabilities represent 66% of the population at BSDC compared to 46.3% in community based programs.⁵

The balance of services provided to individuals with developmental disabilities in Nebraska occurs in what is generally referred to as the "community-based" side. As of June 2008, 4,116 persons received services through the community-based programs. These services include day or vocational services, residential and respite services. Typically, the Division of Developmental Disabilities provides funding for community-based service providers for services specifically designed to meet the needs of persons with developmental disabilities. These services include community supports which are services designed to give the person and his or her family needed assistance. Community support has no requirement of habilitation. Currently there are approximately 3,500 people receiving day or vocational services under this form of service.

³ Testimony of Ron Stegemann, June 23, 2008, p. 74.

⁴ These percentages reflect the current composition of individuals residing at BSDC. As residents from BSDC are moved into community-based settings, the mild disabilities as a percentage of the overall BSDC population will go down and the percentage of profoundly disabled and those with difficult behavioral issues is expected to increase.

⁵ Testimony of Dr. Lee Zlomke, June 23, 2008, page 61.

Community-based programs also include what are known as “day and residential” services. Day and residential services, in turn, are broken down between assisted or supported services. Assisted services are typically provided in a group setting where staff are providing services to more than one individual on an ongoing basis. Assisted residential services are delivered to individuals who require the ongoing presence of providers staffed to meet the residential needs. Assisted residential services may take place in a group home setting or an apartment where two or three individuals live with staff present whenever they are at home. By contrast, supported residential services are delivered to individuals who require the presence of staff only intermittently to meet their residential needs. This is typically found with individuals who are more independent and can live in an apartment or a house without supervision most of the time either because they have natural supports in place or their higher level of functioning lends itself to less supervision.

In both types of residential services the community-based provider is expected to provide habilitative training and supports which typically include teaching skills such as hygiene, socialization, communication and independent living skills such as budgeting and shopping, cooking, housekeeping and laundry. Further, provider staff may also need to support individuals in either setting with transportation and duties such as check writing, handling the mail, medication administration and attending to doctor appointments.

Assisted day services also come under the umbrella of community-based care. Assisted day services are provided to individuals who require the ongoing presence of providers staffed to meet their needs during normal work hours. These services may take place in a sheltered work shop, or during work crew activities such as on a mowing crew or a janitorial crew in a local business. This service also includes work stations in industry where provider staff may operate a work crew in a factory setting.

Specialized respite care is also available through community-based providers. This service provides families with trained staff for short breaks from caring for their loved one. There are currently 480 families receiving this service. Finally, there are community support programs which fall within the category of community-based services. These programs allow family and guardians to hire their own personal provider to meet their needs. This category of supports includes assistive technologies, home modifications and vehicle modifications. There are approximately 60 persons in the community availing themselves of the community support program.⁶

LEGAL AND REGULATORY FRAMEWORK

The legal and regulatory framework which governs the state’s responsibility for care of individuals with developmental disabilities begins with the United States Constitution but also includes federal law, federal regulations and state law.

⁶ Testimony of Karen Kavanaugh, June 23, 2008, pages 88-91.

Duty Owed to Persons in an Institutional Setting

The 14th Amendment to the United States Constitution as well as the Americans with Disabilities Act of 1990 set forth the three paramount duties owed to a person receiving care in an institutional setting. The first, and perhaps most important duty, is the duty of protection. People who reside in an institution such as the Beatrice State Developmental Center have a constitutionally protected liberty interest in safety. The United States Supreme Court in *Youngberg v. Romeo*, 457 U.S. 307 (1982), held that the state has an unquestioned duty to provide reasonable safety for all residents within the institution. This duty of reasonable safety extends to protection from unreasonable restraints which includes both chemical and mechanical. This duty also requires that the state provide appropriate and adequate medical care, food, and shelter. Similarly, this duty requires that the state provide an environment free from verbal abuse and humiliation as well as freedom from physical assault and abuse.⁷ The duty to provide a safe environment is violated when an individual at BSDC is placed in danger of physical or psychological harm as a result of inadequate staffing, inadequately trained staff or inadequate supervision.

The second duty, which also has its origins in the United States Constitution, is the requirement that those individuals who reside at a facility such as BSDC receive training or habilitation. In *Youngberg*, the Court recognized that persons with developmental disabilities have a constitutional right to minimally adequate training. The essence of this requirement is regular systematic provision of activities and programs designed to help develop new skills, and maintain skills that have already been learned. The measure for whether or not the state has met its duty to provide training and habilitation is whether or not the facility's practices substantially comport with generally accepted professional practice. The measure of "generally accepted professional practice" is, in turn, found in the CMS regulations that are discussed below as well as the expert opinions of providers in the field as to the prevailing standards of care.

The third duty owed by the state to individuals receiving care in an institutional setting is the mandate of integration. This duty arises not so much from the Constitution as it does from the Americans with Disabilities Act of 1990 as interpreted in *Olmstead v. L.C.*, 527 U.S. 581 (1989). In *Olmstead*, the U.S. Supreme Court held that undue institutionalization qualifies as prohibited discrimination by reason of disability under the public service portion of the ADA. The Court came to this conclusion for two primary reasons, both of which are important to fully understand the breadth and the limitations of the *Olmstead* decision. First, the Court recognized that the continued institutional placement of persons "who can handle and benefit" from community settings perpetuates unwarranted stigmatizing assumptions that the persons so isolated are incapable or unworthy of participating in community life. Secondly, the Court reasoned that confinement in an institution, such as BSDC, severely diminishes the every day life activities of individuals including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

⁷ Our own state law, Neb. Rev. Stat. §83-1,202(8), recognizes that the first priority of the state to persons with developmental disabilities should be to ensure that such persons have sufficient food, housing, clothing, medical care and protection from abuse or neglect.

Olmstead is very clearly an important decision from the United States Supreme Court as it relates to providing care to individuals with developmental disabilities. Ultimately, *Olmstead* stands for the proposition that professionals must conduct reasonable assessments in determining whether a person residing at a center such as BSDC is either (1) able to handle or (2) can benefit from, community settings. If, based on that assessment, the individual is found to be either able to handle, or benefit from, community settings, that resident is a qualified individual within the meaning of the ADA and the duty to integrate him or her in the community arises. This duty to integrate, however, is not an unqualified mandate for placement in community settings. In fact, the duty to integrate is subject to a qualification found in federal regulations at 28 C.F.R. 35.130(9)(e)(1), 1998 which states that: “Nothing in this part shall be construed to require an individual with a disability to accept an accommodation which such individual chooses not to accept.” The regulations further provide that persons with disabilities must be provided with the option of declining to accept the particular accommodation. “Accommodation” as used in the context of an individual with developmental disabilities in an institution is placement in a community setting.

What is evident from the duty imposed by the ADA, and the qualification of that duty found in the Code of Federal Regulations, is that where an individual is able to handle or can benefit from the community setting, the state has a duty to place them in such a setting rather than leave them in an institution but that duty is subject to the right of the institutionalized person to decline the accommodation, which is to say the individual may decline to be transferred to a community setting.^{8 9}

Federal Regulatory Oversight of ICF/MR’s

Beyond the United States Constitution and the ADA, the primary regulatory process in place for ICF/MR’s is found in the rules and regulations of CMS. Because the State of Nebraska receives well over half of its funding from the federal government for the operation of the ICF/MR’s, including BSDC, CMS was put in place to provide regulatory oversight of such facilities.

The regulatory process employed by CMS involves eight “conditions of participation”. These eight conditions of participation are the overriding principles which govern CMS’s evaluation of the performance of ICF/MR’s across the country. Those eight conditions of participation are:

- (1) Governing body management
- (2) Client protections
- (3) Facility staffing
- (4) Active treatment services

⁸ Testimony of Bruce Mason, June 23, 2008, pages 23-27.

⁹ As the State of Nebraska attempts to reduce the census at Beatrice State Development Center, one can easily imagine an individual who is able to handle or can benefit from a community setting but whose guardian is unwilling to agree to placement outside of BSDC. Witness-attorneys Bruce Mason and Jodi Fenner provided the committee with a thoughtful discussion on a process and procedure which might be employed in those instances where the state believes placement in a community setting is appropriate but is unable to secure the permission of the individual’s guardian. See testimony of Bruce Mason and Jody Fenner, June 23, 2008, pages 22-54.

- (5) Client behavior and facility practices
- (6) Healthcare services
- (7) Physical environment
- (8) Dietetic services.

In addition to the eight conditions of participation, there are 56 standards. These standards provide the measure by which ICF/MR's receiving federal funding are judged.

It is important to note that the duties imposed upon an ICF/MR by virtue of the Constitution and the ADA are separate from the CMS regulations. While the Constitution and the ADA focus on the fundamental rights of the residents of an ICF/MR, the CMS regulations provide the standard of care for how such a facility should be operated.

The process by which ICF/MR's are measured is an inspection of the facility generally referred to as a "survey." Surveys may be conducted by either a state agency or regulators from CMS. The state agency responsible for conducting surveys of ICF/MR's, including BSDC, is the Licensure Unit of the Division of Public Health which, while it is a part of the Nebraska Department of Health and Human Services, stands alone as a separate sub-agency so as to ensure surveys are conducted in an unbiased manner.

The process by which ICF/MR's are surveyed, regardless of whether it's undertaken by the state or CMS, generally involves an onsite visit to the facility, typically over a period of days. The survey will include onsite observations as well as file and record reviews. Once a survey is complete, any deficiencies, or breaches in the standards of care, are presented to the facility, which is then provided an opportunity to respond with a plan of correction. Generally speaking, the plan of correction is provided within 90 days and sets forth the institution's plan to resolve the deficiencies.

In addition to regular surveys, ICF/MR's are subject to two additional surveys. One is what is referred to as an "immediate jeopardy" survey. As the name would suggest, immediate jeopardy surveys are conducted in response to a situation in which a client is found to be in immediate jeopardy of danger or injury. These surveys focus on the condition or situation that presents an immediate danger to a resident. The other type of survey is a follow-up survey. These surveys are typically done to determine whether or not an institution who has provided a plan of correction has actually followed through on that plan of correction and resolved the deficiency found at the time of an annual or immediate jeopardy survey.

State Law

In addition to the requirements of the United States Constitution and the ADA, state law relating to individuals with developmental disabilities is derived from the Developmental Disabilities Services Act which is found at Neb. Rev. Stat. §83-1,201 through 83-1,227.

Oversight of Community-Based Programs

In contrast to regulations that apply to ICF/MR's, community based oversight is characterized by far fewer regulations and much less frequent inspections.

Where ICF/MR's are subject to CMS regulations, community-based programs are subject only to state regulations which are nowhere near as comprehensive as their federal counterpart. Similarly, where ICF/MR's are subject to annual surveys, surveys of community providers which are done by the Nebraska Department of Health and Human Services occur only every four or five years.

Beyond the state's regulatory process, the cornerstone of the oversight of community-based programs is found in three safeguards. The first safeguard is the certification process. Most, but not all,¹⁰ providers must be certified by the Nebraska Department of Health and Human Services before they can provide services to individuals with developmental disabilities. That certification process requires that a provider demonstrate compliance with applicable state standards for the care and treatment of individuals with developmental disabilities.

The second safeguard with respect to community-based care is the monitoring of services by each individual's service coordinator. Those receiving services in the community are provided with a service coordinator. The service coordinator is responsible for ensuring that various services such as residential transportation, medical, dental, etc. are provided to those with a community-based placement. These service coordinators have regular contact with their clients and it is the prevailing view in the industry that service coordinators provide an effective measure of oversight as they carry out their responsibility to those placed in a community setting.

Those in the community-based provider industry also point to an additional safeguard for those with a community-based placement. The industry believes that families and the clients themselves provide a measure of oversight. For those who are placed in residential facilities, many are frequently seen by family members who, when the occasion arises, can express concerns or complaints to service coordinators regarding the level of care or the presence of problems in a particular placement. Similarly, many of those placed in the community are higher level functioning adults. Because of their higher level functioning, many hold jobs and otherwise come into contact with other adults besides their care providers. This affords the client an opportunity to express concerns regarding their placement such as occasions of abuse and neglect that may occur in a residential setting.

¹⁰ Facilities with fewer than 4 beds do not require certification.

HISTORY OF BSDC

The history of Beatrice State Developmental Center generally parallels the prevailing attitudes towards the mentally retarded. When BSDC was established in 1885, it was known as the Nebraska Institution for Feeble-Minded Youth (NIFMY). The purpose of the facility was to provide shelter and protection for those who were generally referred to as “imbecile or feeble-minded.”

In keeping with the then prevailing attitude that individuals with mental retardation should be segregated and warehoused, the Legislature, in 1915, passed three laws touching the lives of those individuals. First was a law which provided for the sterilization of individuals with mental retardation. The second law provided for the civil commitment to NIFMY of individuals with mental retardation. Finally, the legislature mandated that NIFMY accept people who were judicially determined to be “idiot, imbecile or feeble-minded.”

The role of BSDC continued to track prevailing norms for the balance of the 20th Century. By the late 1960's, 2,300 people lived at BSDC in what were generally dormitory-styled settings which had a capacity for only 800. The overcrowding at BSDC led inevitably to a lack of training and habilitation for residents. Those who were higher functioning often were providing care to the more vulnerable.

BSDC, as did most state facilities around the country, continued to warehouse people with mental retardation with little changing until 1972 when a class action was filed in the United States District Court for Nebraska. (*Horacek v. Exon*, 375 F.Supp. 72 (D. Neb. 1973)). The class action challenged the underlying assumptions that prevailed at BSDC and the operation of the center that reflected assumptions made about the residents.

After three years of litigation, the federal court entered a Consent Decree approving the settlement entered into between the class of private plaintiffs and the State of Nebraska. The *Horacek* Consent Decree recognized the constitutional rights of individuals with mental retardation at BSDC. Their constitutional rights extended to protection from physical and psychological harm as well as their right to habilitation. The Consent Decree also called for the reduction of the population from approximately 1,200 to a “goal” of 250 within three years.

For a time, primarily in the 1990's, the Beatrice State Developmental Center represented the gold standard of care for those receiving treatment in an institutional setting. By 2001, problems at the Beatrice State Developmental Center began to emerge once again as documented in surveys done by CMS from 2001 through 2007. The shortcomings of the Beatrice State Developmental Center came to a head with the finding by the Department of Justice in 2008 that the civil rights of residents of BSDC were violated as a result of regular instances of abuse and neglect at the facility. In addition to the findings of the Department of Justice, CMS, after providing the State with repeated opportunities to correct the problems of BSDC concluded, following a November 2007 survey, that BSDC was so far out of compliance with the conditions of participation that decertification was an appropriate remedy. As a consequence, the Beatrice State Developmental Center was decertified by CMS on December 5, 2007. As a consequence of the decertification, the State of Nebraska lost over half of the funding to operate BSDC or

approximately \$28.5 million. Finally, the decision by CMS to decertify BSDC has been appealed by the State of Nebraska. A hearing on that appeal was held November 19, 2008 before an Administrative Law Judge who is not expected to provide a decision any sooner than June, 2009.¹¹

¹¹ This brief history of BSDC is a summary of the HISTORICAL ORIGINS OF THE BEATRICE STATE DEVELOPMENT CENTER found in the report An Indictment of Indifference prepared by Nebraska Advocacy Services, Inc., December 5, 2007. For a more thorough treatment of the subject matter, refer to this document found at “E” in the appendix attached to this report.

FAILURES AT BSDC

The Beatrice State Developmental Center has been the subject of two separate federal investigations. While each of the federal investigations have different criteria for evaluating the performance of BSDC, they have, through different approaches, come to the same conclusion: that BSDC has failed the residents at a very fundamental level.

The reports of the DOJ and CMS have been the subject of much discussion and media coverage over the last year. Nevertheless, they provide the most thorough assessment of the Beatrice State Developmental Center and, for that reason, the committee feels that a summary of their findings is appropriately incorporated into this report.

Department of Justice

The Department of Justice initiated an investigation into the Beatrice State Developmental Center pursuant to the Civil Rights of Institutionalized Persons Act (“CRIPA”), 42 U.S.C. §1997. The focus of an investigation pursuant to CRIPA is patterns and practices of conduct that violate the constitution or federal statutory rights of persons with developmental disabilities who are served in public institutions.

From October 15 through 19, 2007, the Department of Justice conducted an in-depth, on-site review of BSDC with the benefit of expert consultants in the areas of protection from harm, training and behavioral services, psychiatry, healthcare, and nutritional and physical management. Their on-site investigation included interviews with administrators, professionals, staff and residents. The investigation also included observations of residents in a variety of settings. The Department of Justice has concluded “that numerous conditions and practices at BSDC violate the constitutional and federal statutory rights of its residents. In particular, [the Department of Justice found] that BSDC fails to provide residents with adequate: (A) protection from harm; (B) training and associated behavioral and mental health services; (C) healthcare, including nutritional and physical management; and (D) discharge planning and placement in the most integrated setting.”¹²

The DOJ Report concluded “BSDC residents are subjected to abuse and neglect and suffer a high number of incidents that often result in injuries or other poor outcomes. We found consistent patterns of staff actions that often subjected residents to repeated preventable injury.” The safety consultant involved in the DOJ investigation concluded that “the nature of many abuse and neglect allegations, and the frequency with which they are made, suggests a “culture undercurrent that betrays human decency at the most fundamental levels...basic human dignities are violated with considerable regularity at BSDC.”¹³

With regard to the risk of harm to residents, the DOJ observed: “Lack of adequate staff supervision, environmental and safety concerns, as well as the failure to provide adequate behavior and mental health supports all contribute to an increased risk of harm for many

¹² Letter from DOJ to the Honorable David Heineman dated March 7, 2008. (p. 2) (hereinafter DOJ Report)

¹³ DOJ Report p. 4.

residents on a day to day basis.”¹⁴ The report detailed an alarming number of fractures and injuries caused by resident to resident aggression as well as a failure to develop and implement safeguards to reduce the frequency of resident falls. Indeed, the report noted “most of the resident injuries appear to occur due to inadequately addressed behaviors – sometimes from self-injury, and sometimes from unchecked aggression of another resident.”¹⁵

The Department of Justice also recognized that many of the residents at BSDC have medical conditions which compromise the ability of the residents to swallow and digest their food and beverages. Notwithstanding these medical conditions, the DOJ found “several instances in which staff failed to adequately protect residents from consuming food or fluids that could cause them serious harm.”¹⁶

The DOJ’s exhaustive report focused a great deal of attention on “staffing concerns.” In relevant part, the report concludes the following with respect to staffing concerns at BSDC:

Many of the deficiencies at BSDC with regard to safety are linked to staffing difficulties. Our safety consultant characterized the BSDC work force as ‘wrought with exhaustion and discontent’. She reported that some employees pleaded for help in order to acquire adequate staffing assistance for the health and welfare of the residents. During our visit, BSDC’s staff expressed concerns about being assigned to work with residents without being trained on how to properly support and care for them. They also told us about their concerns relative to unsafe working conditions due to severe staff shortages, employee exhaustion, and lack of adequate training, and disgruntled co-workers...

During the week of our visit in October 2007, the facility had vacancies in 117 of 411 direct care staff positions. In addition to these, there were vacancies for a physician, six nurses, a nurse supervisor, a physical therapist, two team leaders, and two compliance specialists. Many of these positions have been unfilled for months.

Given a large number of staff vacancies, the facility has relied heavily upon requiring current staff to work overtime. BSDC’s records reveal that direct care staff had been working overtime, sometimes on double shifts, for more than a year now...Overtime is often mandatory for current BSDC staff. We spoke to numerous staff who related their concerns about having to work multiple double shifts (16 consecutive hours) within a single week to provide care to residents....

Needless to say, the demands of current BSDC staffing practices placed both emotional and physical stress on the staff that may lead to an environment that is more conducive to abuse, neglect and mistreatment. At the very least, tired and overworked staff will be less likely to take the initiative and responsibility

¹⁴ DOJ Report p. 9.

¹⁵ DOJ Report p. 11.

¹⁶ DOJ Report p. 11.

necessary to provide residents with the programming, care and treatment they need, especially if the residents have difficult behaviors or complex healthcare needs.”¹⁷

The DOJ Report was also critical of BSDC’s response to client behaviors. The report noted that the programs themselves are typically well-developed but the implementation of the programs in practice is inadequate. The implementation deficiencies, in turn, were attributed to staffing difficulties. The report noted that “the behavior programs at BSDC involve multiple distinct steps or procedures. New staff, temporary staff, “on-call” staff, or staff pulled from other units are often unfamiliar with the particulars of the lengthy and detailed individual behavior programs. This leads to faulty implementation. The report also observes that the difficulties with implementation lead to “a rather consistent reaction to behavioral problems, where staff quickly move from behavior response blocking to physical restraints to mechanical restraints.”

After acknowledging that many of the residents at BSDC have a dual diagnosis of mental illness and developmental disabilities, the report observed there are deficiencies with respect to psychiatric care. BSDC’s reliance upon a part-time psychiatrist who provided care two days per month was simply inadequate given the number of individuals with mental health issues as well as the severity of the problems they present with.

The report also observed that BSDC “too often fails to provide residents with adequate healthcare.”¹⁸ As one might expect, the concerns centered on health risks related to “bowel impactions and obstructions, pneumonia and aspiration pneumonia, skin breakdown, seizures and fractures due to osteoporosis.”¹⁹ The report observed that many of these types of health conditions are preventable with proper care.

The DOJ Report then went on to make a series of specific recommendations for improvement.

As a consequence of the investigation conducted by the DOJ, the State and the DOJ entered into a summary agreement in order to avoid “protracted and adversarial litigation.” The summary agreement was the basis of a consent judgment, which was signed and entered as an Order and Judgment of the U.S. District Court for the District of Nebraska by Judge Richard G. Kopf on July 2, 2008. That Consent Decree is found in the Appendix at “C”.

Before reviewing the requirements of the Summary Agreement, it is important to note the relationship between the DOJ and the Centers for Medicare and Medicaid (CMS). Though both the DOJ and CMS have ongoing investigations at BSDC, there is in fact and for all practical matters, no relationship between the two entities. Neither the DOJ nor CMS report to the other, share jurisdiction, or coordinate findings or recommendations. The DOJ derives its authorization to act from the Civil Rights of Institutionalized Persons Act (CRIPA), 42 U.S.C. 1997. CMS derives its authority from its appropriations of Medicaid and Medicare funding. Thus, CMS may cause the State to relinquish its Medicare and Medicaid funding while the focus of DOJ is on the protection of the BSDC residents’ civil rights. It is plausible however to suggest that should the

¹⁷ DOJ Report pages 13-14.

¹⁸ DOJ Report page 25.

¹⁹ DOJ Report page 25.

State remedy the deficiencies cited by CMS, the residents' civil rights would be restored. The State is still required though to meet the intent and spirit of the Summary Agreement.

Summary Agreement

The Summary Agreement is a lengthy document divided into three sections: Legal Framework, Office of the Independent Expert and Remedial Measures. Each section sets forth specific requirements the State has agreed to meet.

The legal framework section not only establishes the jurisdiction of the DOJ to act pursuant to CRIPA but it sets out the timeframes for compliance. Throughout, there are specific measures for the State to accomplish. Unless otherwise noted, compliance with these measures is to begin within 90 days of the filing of the Consent Judgment. Furthermore, the Consent Judgment recognizes that both the State and the DOJ anticipate full implementation of all provisions will take four years. The Court will maintain jurisdiction an additional year to ensure maintenance of the changes.

Unique to the DOJ agreement as compared to the CMS investigation is the appointment of an Independent Expert, John J. McGee, Ph.D. Because the DOJ focus is the protection of individuals' civil rights, an independent expert is appointed to assist the State. The Independent Expert reports directly to the Court. He is required to report at least quarterly to the parties regarding the State's implementation efforts and compliance with the Summary Agreement.

The State is required to notify the Independent Expert regarding any death of a resident; serious incidents, including but not limited to, allegations of abuse and/or neglect; incidents producing a serious injury; incidents involving prolonged physical and/or mechanical restraint; and incidents involving law enforcement personnel. The Independent Expert is to be also provided with copies of discharge plans for residents transitioning out of BSDC.

The last section of the Summary Agreement is the most lengthy as it sets out the steps to be taken to correct those violations of the residents' civil rights. The "Remedial Measures" section covers an exhaustive range of care issues. Again, unless otherwise specified, compliance efforts with these measures were to be underway within 90 days of the Consent Judgment being filed.

While the Committee believes the requirements in the Settlement Agreement provide an appropriate road map for improvements within BSDC, it is impossible to verify the current status of each of these requirements as the Independent Expert has not issued a report to date. The Independent Expert was to provide a quarterly report on October 1, 2008 but the Committee has been informed that his first report will not be available until the end of December.

The DOJ investigations focus on the civil rights of those in institutions and the Department's guidelines are considered more of a "baseline" or "floor," while CMS' standards are more specific. As a consequence, even if all of the requirements of the Settlement Agreement are met, it is possible that CMS will still have specific concerns. It is also the Committee's

understanding that even though there are explicit deadlines in the Settlement Agreement, the DOJ realizes that changes of the type envisioned by the Settlement Agreement will take a considerable amount of time.

Centers for Medicare and Medicaid Services

As noted earlier, BSDC is an “intermediate care facility for people with mental retardation” (ICF/MR).²⁰ As an ICF/MR, and in order to qualify for Medicaid reimbursement, BSDC must be certified and maintain compliance with certain federal standards, known as “Conditions of Participation” (CoPs).²¹

The Centers for Medicare & Medicaid Services (CMS) is the federal agency responsible for ICF/MR certification and compliance. To determine whether a provider is complying with a particular “condition of participation” (CoP), CMS surveyors evaluate the manner and degree to which the provider satisfies each of the standards within the condition.²² A “condition level” deficiency (as opposed to a less serious “standard level” deficiency) is one “where the deficiencies are of such character as to substantially limit the provider's or supplier's capacity to furnish adequate care or which adversely affect the health and safety of patients.” The principal focus of the survey is on the “outcome” of the facility’s implementation of ICF/MR active treatment services.²³ In other words, attention is focused on what actually happens to individuals: “whether the facility provides needed services and interventions; whether the facility insures individuals are free from abuse, mistreatment, or neglect; whether individuals, families and guardians participate in identifying and selecting services; whether the facility promotes greater independence, choice, integration and productivity; how competently and effectively the staff interact with individuals; and whether all health needs are being met.”²⁴

There are several components of the “active treatment process”: (1) a comprehensive functional assessment, (2) an individual program plan (IPP), (3) program implementation, (4) program documentation, and (5) program monitoring and change.²⁵ As part of the initial comprehensive functional assessment, the individual’s interdisciplinary team is to identify all of the individual’s:

- Specific developmental strengths, including individual preferences;
- Specific functional and adaptive social skills the individual needs to acquire;
- Presenting disabilities, and when possible their causes; and
- Need for services without regard to their availability.²⁶

²⁰ According to the Centers for Medicare and Medicaid Services, there are currently 7,400 ICF/MR’s in the United States, which serve approximately 129,000 people. Most of the individuals who receive care provided by ICF/MR’s have other disabilities as well as mental retardation. Many of the people who are served by this program are also non-ambulatory, have seizure disorders, behavior problems, mental illness, are visually-impaired or hearing-impaired, or have a combination of these conditions. “Background and Milestones—Intermediate Care Facilities for People with Mental Retardation (ICF/MR)” available at

http://www.cms.hhs.gov/CertificationandCompliance/downloads/ICF/MR_Background.pdf.

²¹ 42 CFR Part 483, Subpart I, Sections 483.400-483.480.

²² These standards are often referred to as “tags.”

²³ State Operations Manual - Appendix J - Guidance to Surveyors: Intermediate Care Facilities for Persons With Mental Retardation. Available at http://www.cms.hhs.gov/manuals/Downloads/som107ap_j_intermcare.pdf

²⁴ http://www.cms.hhs.gov/GuidanceForLawsAndRegulations/09_ICF/MR.asp

²⁵ 42 CFR 483.440(c)(3), 42 CFR 483.440(c), 42 CFR 483.440(d), 42 CFR 483.440(e), and 42 CFR 483.440(f).

²⁶ http://www.cms.hhs.gov/manuals/Downloads/som107ap_j_intermcare.pdf

The interdisciplinary team is then responsible for preparing an IPP, which includes opportunities for individual choice and self-management, identifies objectives, and includes strategies, supports, and techniques to be employed. The client then receives a continuous active treatment program “consisting of needed interventions and services in sufficient intensity and frequency to support the achievement of IPP objectives,” with a comprehensive functional assessment on an annual basis.²⁷

History of CMS Involvement at BSDC

Both CMS and the Nebraska Department of Health and Human Services (through the Licensure Unit of the Division of Public Health) have conducted surveys at BSDC over the last ten years. In fact, up until 2006, the State of Nebraska completed all of the surveys at BSDC. During 2006 and 2007, CMS used its own surveyors to survey BSDC (except for complaint surveys) and in 2008, CMS again began to partner with the State of Nebraska surveyors when surveying BSDC.

Results of CMS Surveys

There are approximately 2,000 pages of “survey activity” concerning BSDC in the last decade. Since September 2006, BSDC has been surveyed on nine separate occasions, including one full survey, four follow-up surveys to immediate jeopardy situations, three other follow-up surveys, and an incident investigation. BSDC was determined to be out of compliance with seven of the eight CoPs in September 2006, and at all times since, BSDC has remained out of compliance with at least two conditions of participation.

The survey that is the subject of ongoing litigation between BSDC and CMS is the survey with the completion date of November 7, 2007. In this survey, CMS determined that four CoPs were not met and that one deficient standard posed an “immediate jeopardy” (IJ) to client health and safety. The out of compliance CoPs were:

- Governing Body and Management;
- Client Protections;
- Facility Staffing; and
- Active Treatment Services.

As CMS stated, “The facility failed to take appropriate corrective action with substantiated physical abuse cases, with allegations of abuse, neglect and mistreatment, with injuries of unknown source investigations, and with client to client abuse investigations.”²⁸ CMS summed up the situation in this way:

“One begins to see how the various unmet CoPs begin to feed each other: lack of sufficient staff leads to lack of time to train staff, which leads to staff being unfamiliar with the needs of clients, which leads to lack of active treatment programs, which leads to frustrated and disruptive clients, which leads to abuse

²⁷ Id.

²⁸ Respondent’s Pre-Hearing Brief, July 17, 2008.

and mistreatment of clients by staff and by other clients, etc. And it is likely that the staff shortages affected BSDC's unwillingness to adequately discipline staff involved with client mistreatment. BSDC's problems were systemic in nature, which leads to the next, unmet CoP, [Governing Body and Management]."²⁹

CMS notified BSDC that its participation in the Medicaid program would be terminated on March 7, 2008, if the situation was not corrected. A follow-up survey concluding on March 4, 2008 resulted in a determination that five CoPs were not met and that three IJ's existed. A further follow-up survey on March 7, 2008 found that the IJ's had been removed, but that BSDC continued to have condition-level deficiencies (four). CMS then terminated BSDC's Medicaid approval because of its inability to meet the Medicaid CoPs.³⁰

At the June 23, 2008 public hearing, Jodi Fenner, Legal Counsel to the Nebraska Department of Health and Human Services, confirmed an outline of BSDC's recent relationship with CMS:

SENATOR LATHROP: ...[A]s I read the history of our CMS evaluations and the State's response, it looks something like this: CMS comes in and says, these are the problems. The State has responded by saying, we'll do this to fix it. CMS has come in and said, okay, what did you do? And we've said, well, we didn't even get everything done we said we'd do. And they say, you know, you're out of compliance. And then we say, well, we'll do this to get into compliance. And that's been the history since 2001—a series of evaluations, promises by the State followed by more evaluations where we admittedly haven't done what we promised to do and we remain out of compliance.

JODI FENNER: That is correct.

SENATOR LATHROP: And essentially what's happened to us, to us being the State of Nebraska, is that finally CMS said enough is enough. And we had in, I think it was December, we made our last promise and they came in since December and said, we're decertifying you because you've given us promises and you're not fixing the problem. Would that be a fair summary of our relationship with CMS since 2001?

JODI FENNER: I think that's correct.

²⁹ Id. at 10.

³⁰ Because BSDC filed an appeal prior to the termination date, "CMS has held the termination in abeyance, pursuant to Section 1910(b)(2) of the Social Security Act, which provides that a Medicaid provider agreement with any [ICF/MR] that is dissatisfied with the Secretary's determination that the ICF/MR does not qualify for Medicaid participation and that has requested a hearing, will continue in effect until a hearing decision is issued by the Secretary." Id. at 2.

CMS' Discussions with the Committee

The Committee also met with representatives from CMS in an unrecorded meeting. Based on this meeting, it is the understanding of the Committee that on average five percent of facilities are out of compliance with one or more of the eight CoPs nationwide. The Committee also understands that the only other facility that did not meet seven out of the eight CoPs was in Illinois, five years ago. There has been only one facility besides Nebraska that has had its funding terminated.

As mentioned above, at the time of the September 2006 survey, BSDC was found to be out of compliance in seven of the eight CoPs. As a result, CMS recommended consultation because the methods that BSDC were using were outdated. BSDC reacted slowly to this recommendation but eventually brought in a consultant. In the end however, the facility was unable to make necessary changes and the November 2007 survey found that BSDC still remained out of compliance with four of the CoPs. As a result, CMS began the termination process.

One of the main concerns expressed by CMS was, though there appeared to be a will to make changes, there was little or no follow-through. CMS provided BSDC with many opportunities to make necessary changes but even during its most recent survey in April 2008, BSDC remained out of compliance with three CoPs. In most cases where a facility is found to be out of compliance with a CoP, it is given 90 days to show improvements. In the case of BSDC, it has been given over 500 days by CMS. While CMS indicated that the plans of correction have improved, they were still not satisfied with the changes at the facility.

Nebraska Advocacy Services, Inc.

In December 2007, Nebraska Advocacy Services, Inc. (NAS) issued a report concerning its own ongoing investigation of BSDC.³¹ NAS is "federally mandated to provide legal and other advocacy services on behalf of persons with disabilities, including persons with developmental disabilities and persons with mental illness." It is further authorized to investigate potential abuse or neglect, as well as the health and safety of individuals with developmental disabilities in both institutional and community settings.³²

NAS has reviewed the CMS surveys dating back to 2001, and since November 2006, its legal advocacy staff has visited BSDC twice a month to conduct inspections and on-site reviews. While NAS documented a history of problems at BSDC in its report, it provided extensive details of BSDC's most recent and relevant failures in 2006-2007.³³

31 The NAS report, "An Indictment of Indifference--A Report of the Investigation of the Beatrice State Developmental Center By Nebraska Advocacy Services, Inc.," is attached.

32 Federal statutes, including the Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. Sect. 15001 et. seq.

33 The chronology of NAS's investigation is contained on pages 21-24 of its report.

In its report, NAS incorporates the CMS findings and conclusions from 2006-2007, confirming the CMS findings from its own ongoing observations, analyses, inspections, record reviews, and consultations. In sum, the practices at BSDC have, according to NAS, “substantially departed from accepted professional standards of care” in violation of federal law and regulations. “The evidence is clear that Nebraska state officials failed and continue to fail to provide adequate active treatment/habilitation for residents at BSDC; rather, staff convenience necessitated by chronic understaffing drives habilitation.”³⁴

Summary of DOJ, CMS and NAS Investigations

While the Committee has provided a summary of the DOJ, CMS and NAS findings, it is important to remember that these summaries are supported by very troubling instances of abuse and neglect at BSDC. A few examples of how those instances of abuse and neglect impact the lives of the residents at BSDC are set forth below. These are merely examples. Unfortunately, the CMS, DOJ and NAS reports are replete with equally appalling instances of abuse and neglect visited upon the residents at BSDC as a consequence of the systemic failures at the BSDC:

BSDC investigators substantiated mental abuse of resident WC after concluding that staff engaged WC in a “game” of what could be called “canine catch” in August 2007. This involved staff tossing WC’s pop bottle across the room, instructing the resident to retrieve or “fetch” the bottle, and then return it. After repeating this “game” at least twice, a staffer was observed hiding the bottle behind her back while motioning WC across the room to find the bottle. Not realizing that the staffer had the bottle, WC ran around the room aimlessly searching for it.

BSDC investigators substantiated both mental and physical abuse of resident UA, who requires enhanced staffing to meet his needs. In June 2007, a direct care staff worker began to taunt and upset UA while playing a board game. After the resident reached out in frustration, the staffer retaliated by shoving UA and knocking him to the floor, causing a purple bruise to the resident’s right elbow.

BSDC investigators substantiated both mental and physical abuse where, in April 2007, a male staff worker “slammed” resident TW into a wall for pretending to take a female staff worker’s lunch item. After the push, TW became sad, went to the bathroom, and cried. TW said the altercation “knocked the wind out” of him. BSDC confirmed three prior allegations of physical abuse of this resident by the same staff worker in the prior nine months.

BSDC investigators substantiated both verbal and physical abuse by a staff worker against resident SV, who uses a wheelchair. In April 2007, the staff worker observed SV start to spit out medicine she had given to him. The staff worker used demeaning names to address the resident and then held the resident’s head against the headrest on his wheelchair, forcing a spoon into his mouth; after that, she

³⁴ Page 3.

forcibly held a washcloth across SV's mouth, trying to make him swallow. According to an eyewitness, this situation continued for 10 minutes.

BSDC investigators substantiated verbal abuse of resident RU by a staffer in June 2007. While taking a resident's blood sugar reading nearby, a nurse overheard a staffer talking to RU in the adjacent bathroom. The nurse reported that the staff worker verbally abused RU while he was bathing, saying: "God damn it, don't you know how to take a bath?" As the resident began to cry, the staffer then said: "So now you think you are going to cry like a b__ch and that is not going to help you out one bit. Let's get this done."

BSDC investigators substantiated neglect by a direct care worker who, in August 2007, failed to bathe, check, change diapers, or re-position six residents assigned to her care; instead, BSDC investigators found that the staffer watched television and slept during her work shift.

BSDC investigators substantiated neglect where, in August 2007, four staff workers in one unit failed to check or change resident OR for four-and-a-half hours. During that time, none of the staff re-positioned the resident, interacted with him, completed his treatments, or conducted his programs. The staff of the next shift discovered OR to be soiled and completely soaked in urine, through his clothes.

BSDC investigators substantiated neglect where, in July 2007, two staffers had placed resident NQ in her bed for a nap and then left with four other residents for a trip to a softball game. The resident, who should have been checked and changed every two hours by staff on duty, was discovered five hours later still in her bed in the same attire as before, with her clothes and bedding soaked in urine."³⁵

³⁵ DOJ Report pages 4-6.

IDENTIFIED PROBLEMS/CONCERNS

Needless to say, the reports from DOJ, CMS and NAS document a horrible state of affairs at BSDC. These reports also document the fact that the problems at BSDC did not develop overnight.

The Committee heard repeatedly how BSDC represented the gold standard in providing care to those with developmental disabilities in the 1990's.³⁶ By contrast, the surveys which began in 2001 as well as the reports of the DOJ and NAS chronicle the deteriorating conditions from 2001 through 2007 culminating in an intervention by the United States Department of Justice, which concluded that care at Beatrice State Developmental Center violated the constitutional rights of the residents, as well as the conclusions of CMS which led to the decertification of BSDC as an ICF/MR and the loss of over \$28,000,000 in funding.

These reports also document that little, if anything, was done to interrupt the development of this crisis before the intervention by the Department of Justice and the decertification by CMS. Since that time, the administration has stepped up its efforts to address the deficiencies of BSDC. It is the considered opinion of the Committee that the attempts by the administration to “clean up” the “Beatrice problem” are, in many instances, too little too late. Indeed, many of the efforts to correct the problem are misguided and are most certainly doomed to failure.

As an overall observation, there is a philosophical failure in the State's approach to resolving the issues that plague BSDC. We believe the proper approach to the resolution of the deficiencies at Beatrice State Developmental Center begins with the recognition that our goal should be to return the State's system of delivering services to individuals with developmental disabilities to the place of prominence it enjoyed in the 1990's. By contrast, the approach by the State might best be characterized as “what's-the-least-amount-we-have-to-do-to-get-by”. For reasons more specifically set forth in the discussion which follows, we believe this approach sets Nebraska on a course that will not satisfy CMS nor provide the services individuals with developmental disabilities deserve.

In the discussion that follows, the Committee more specifically sets forth specific findings and concerns with respect to the delivery of services to individuals with developmental disabilities in the State of Nebraska. As indicated in the introduction, our investigation necessarily involved a review of the waiting list and services provided in the community setting. For that reason, our findings and concerns will likewise address these two important subjects.

The State's Strategy for CMS Re-Certification

As a consequence of the CMS survey completed November 7, 2007, the Centers for Medicare and Medicaid Services decertified BSDC. The result was a loss of over \$28,000,000 in funding annually for an institution with a budget of just over \$50,000,000. The State's approach

³⁶ Testimony of Dr. Lee Zlomke: “Well, when I felt we were at our very best, when other facilities across the country came here to see how we did active treatment and psychological services, was in the early to mid 90's.” (Testimony of Dr. Lee Zlomke, June 23, 2008, page 64). See also, testimony of Ron Stegemann, June 23, 2008, p. 80, as well as the testimony of Joan O'Meara, August 21, 2008, page 5.

in the wake of the CMS decertification is what may fairly be described as the “recertification strategy”. That approach may be summarized in this way:

- (1) Appeal the decision of CMS to decertify. The appeal will allow federal funding to continue pending a decision. It also permits the state to “buy time” which will allow more time to resolve the problems at BSDC.
- (2) “Right size” BSDC. The hallmark of this element is to reduce the population of BSDC to a point where the once understaffed facility has enough employees to serve the smaller population of residents.
- (3) While the CMS appeal is pending, apply to CMS to have BSDC recertified.

The state’s recertification strategy is troubling in a number of respects which are evident as the particular consequences of this approach are examined.

The state has appealed the decision of CMS to decertify BSDC. During the pendency of the appeal, CMS funding will continue. The appeal, which was argued November 19 and 20, 2008 before an Administrative Law Judge, is not expected to result in a decision until sometime in the summer of 2009.

It is the collective judgment of the Committee that the State’s prospects for prevailing in this appeal are dim. The nature of the appeal is such that the only question for the Administrative Law Judge to decide is whether or not the State was in “substantial compliance” at the time of the November 7, 2007 survey. As a consequence of the State’s track record leading up to the November 7, 2007 survey as well as the fact that the State was out of compliance with four out of eight conditions of participation, it is unlikely that an Administrative Law Judge will conclude that the BSDC was in “substantial compliance” at the time of the November 7, 2007 survey.

Perhaps because the State has come to the very same realization as the Committee, the State’s strategy includes a fallback position. The State’s position, as it anticipates an adverse decision from the Administrative Law Judge, is to make various staff and managerial changes at BSDC and attempt to secure CMS recertification at some point before an adverse decision by the Administrative Law Judge. The problem with the “recertification strategy” is the approach taken by the State is not likely to result in recertification by CMS.

The State’s approach to resolving the “problems” at BSDC in anticipation of recertification is to reduce the number of people living at BSDC from just over 300 as of the spring of 2008 to 200 by the end of December 2008.³⁷ To reduce the population at BSDC, the State will offer BSDC residents an opportunity for “community placement.” Community placement has led to the placement of many residents in nursing homes. The balance have been or will be offered opportunities to live in a residential facility operated by community-based providers.

³⁷ The current census at BSDC is 250.

The task of moving residents from BSDC to the community on a voluntary basis ultimately results in a process by which community-based providers sort through the BSDC population for patients for whom care can be provided within the financial limitations imposed by the State's formula for reimbursement of providers. The consequence to the population at BSDC is that the patients with the fewest needs and the less injurious behaviors are moved to the community first. The other side of that equation is that when the State reaches its goal of reducing the BSDC population to 200, those who remain will be those with the most profound health and developmental disabilities and those with the most difficult behaviors. Ultimately, this sorting out process may help BSDC to limit its services to those for whom services should be provided at an ICF/MR, but the process results in an unintended consequence. By reducing the population to 200 of the more difficult cases, the State has made the prospects of recertification in a future survey more difficult. When CMS returns to conduct a survey for recertification, it will be observing care provided to patients with the most difficult behaviors and the most profound disabilities. Similarly, file reviews which will be conducted as part of the survey will involve the files of the State's most problematic individuals with developmental disabilities.

The problem with a strategy that involves reducing the population and seeking recertification was best described by a Kentucky official involved in implementing a similar strategy following decertification by CMS. This official indicated that once a state run ICF/MR has been decertified, and the decision has been made to seek CMS recertification, several things are important to understand. First, because the facility has been decertified, recertification by CMS will necessarily involve a survey which will be conducted at a higher level of scrutiny. The apparent CMS logic behind this heightened level of scrutiny is that if a state run ICF/MR has been decertified, it has been found to be out of compliance on conditions of participation on multiple occasions and tendered plans of correction have not been implemented as promised. Thus, the history of failures justifies the heightened level of scrutiny.

In addition to the higher level of scrutiny by CMS in the recertification process, recertification will now involve observations of care provided to a more difficult cohort of patients. Thus, the combination of a higher level of scrutiny at a time when care is provided to a more challenging population make this strategy questionable at best.

The Kentucky official offered two other observations relative to the recertification process. First, CMS will not pass a state ICF/MR with a "gentleman's C." In other words, recertification will not happen because BSDC was found to be "good enough." Recertification will only happen if fundamental changes occur which address the shortcomings at BSDC as measured by the CMS standards.

The second observation made by the Kentucky official is that recertification will not happen without a substantial commitment of resources. The problems that lead to decertification are deep, substantial and systemic. These types of problems will not be rectified by rearranging staff and offering more excuses for failures to meet CMS standards.

It is the committee's observation that the necessary commitment of resources has not been made by the State of Nebraska. Rather, the State has adopted an approach, with only a few

exceptions, in which changes are made at BSDC only when they can be made without the expenditure of anything greater than nominal resources.

In summary, we believe the “recertification strategy” is not likely to succeed. This strategy has inherent flaws in its reasoning that diminish the chances of success. The strategy has at its foundation the assumption that the State is able to resolve the CMS deficiencies by the time the recertification process is undertaken. The Committee has grave doubts about the State’s ability to resolve all of the issues facing BSDC, particularly the staffing issues which are central to the greatest share of problems identified by CMS and the DOJ. Because resolution of the staffing issues is central to the success of the State’s attempts at recertification, those issues will be addressed in more detail in the following section.

Staffing Issues

Both the DOJ and CMS identified staffing problems as central to the problems at BSDC. As the DOJ observed, “the facility had vacancies in 117 of 411 direct care staff positions. In addition to these, there were vacancies for a physician, six nurses, a nurse supervisor, a physical therapist, two team leaders and two compliance specialists.”³⁸ These vacancies were in addition to the direct care staff positions whose numerous vacancies led to the well-documented overtime hours at BSDC. The numerous vacancies, in turn, resulted in the failure of the state to meet the CMS conditions of participation and were, according to the DOJ, a significantly contributing circumstance to the numerous cases of abuse and neglect.

The Committee appreciates the fact that the administration has filled a good number of management and professional care positions over the course of the last twelve months. Indeed, the state has filled the following managerial and professional staff positions since the November 7, 2007 survey:

- One Orientation Facilitator
- One Medical Director
- One Nurse Practitioner
- Speech Pathology*
- Physical Therapy*
- Psychology*
- Neurology*
- Psychiatry*
- Nutritional Management*
- Medical Chart Reviews*
- Neighborhood Services Administrator*
- QI Director*
- Active Treatment Administrator*
- Investigations Administrator*

* Filled by contract worker.

³⁸ DOJ Report page 13.

Nevertheless, the following managerial and professional staff positions remain unfilled:

- Two Activity Specialists
- Four HSS Treatment Team Leaders
- Two Human Service Treatment Specialists I
- Two Human Service Treatment Specialists II
- Three Licensed Practical Nurses II
- Four Nurses II
- One Nurse Supervisor
- One Physical Therapist II
- Two Psychologists/Clinical
- One Security Chief
- One Social Worker II
- One Speech Pathologist II³⁹

Notwithstanding the improvements at the managerial and staff level, shortages at the direct care staff positions continue. As measured by all overtime hours, BSDC still continues to use 11,000 hours of overtime as of September 2008.⁴⁰

The ongoing problems with staffing are particularly frustrating for the Committee. In the 2008 legislative session, Senator Kent Rogert introduced, and the legislature passed AM 2451 to LB 959 which provided for \$1.5 million to be used for recruitment and retention at BSDC. Notwithstanding the specific purpose to which this money was appropriated, only \$123,000 has been spent on recruitment and retention. Over \$688,000 has been spent on temporary help.

The failure to use the appropriated funds for recruitment and retention is particularly concerning given that shortages of direct care staff persist. These direct care staff are the individuals with face to face, day to day contact with the residents of BSDC. The failure to have sufficient numbers of direct care staff is at the core of the issues identified by the DOJ and CMS. The requirement of mandatory overtime as a substitute for sufficient staffing has been identified as the principal reason for abuse and neglect of residents, failure to provide active treatment to the residents, and appears as the principal reason for failure to provide adequate staff development at BSDC.

To be sure, there are challenges hiring people to serve a community of individuals with high needs and behaviors. The problems are compounded by the fact that BSDC is situated in a smaller community. Nevertheless, these staffing issues have been identified as problems in surveys and investigations conducted well over a year ago and there is simply no excuse for the fact that they persist.

The difficulties with staffing at BSDC are not limited to the nature of the work and the small town setting in which BSDC finds itself. There are many issues which persist which

³⁹ More detailed information on these positions can be found in the October 8, 2008 Settlement Letter that is found in the Appendix to this Report at "G".

⁴⁰ HHS information supplied to the fiscal office.

contribute to the difficulty in fully staffing BSDC. Some of those problems are identified in the section which follows.

BSDC As An Employer

The Committee had occasion to conduct hearings at BSDC. Employees at all levels were encouraged to provide input about BSDC. In addition to employee input at hearings that were conducted at BSDC, direct-care employees were provided surveys by the Committee. The purpose of the surveys was to provide the Committee with a sense of employee perceptions of the work place at BSDC. The results of the survey can be found in the Appendix at "I".

The input from employees at BSDC provided important insight into the difficulties management experiences filling vacancies at BSDC. Employees told us time and again that at one time BSDC was regarded in the Beatrice community as a good place to work. Indeed, we heard many stories of generations of family members serving individuals with developmental disabilities at BSDC. Witnesses spoke frequently of the former reputation of BSDC as a good job for members of the Beatrice community.

The change in this perception in Beatrice is a significant contributing circumstance to the difficulties BSDC faces in filling vacancies. Concerns expressed by employees relate to a change in the "culture" at BSDC. Employees more often than not feel left out of the process. Several employees testified that questions, concerns and suggestions went up the organizational chart but no response or feedback was ever provided by management.

Interestingly, most employees, and the employee union representative, indicated that the rate of pay was not the most significant issue to employees at BSDC. The biggest impediment to job satisfaction related to the issues of culture, the absence of an engaged management and management's abuse of mandatory overtime.

Employees repeatedly expressed concern regarding disciplinary practices at BSDC as affecting their job satisfaction. To be sure, BSDC must necessarily employ a zero tolerance policy for abuse and neglect. On the other hand, the circumstances in which employees find themselves in what is generally referred to as a "west Texas vacation" is problematic. In each instance in which a resident makes an allegation of abuse or neglect, an employee is suspended pending an investigation. During the first six days of suspension, the employee is not paid by BSDC. They are paid for subsequent days until the investigation is complete. If they are exonerated, they do receive back pay for the first six days.⁴¹ In the meantime, the employee has had their stream of income interrupted while at the same time they have been instructed to wait by the phone for the results of the investigation into the allegations of abuse and neglect.

While BSDC certainly has a duty, consistent with its zero tolerance policy, to separate the accuser from the accused during the pendency of the investigation, nothing prevents the employees from being reassigned to administrative positions pending the completion of the investigation. This would, in the Committee's judgment, appear to be a better course of practice from the point of view of employee morale as well as a cost saving measure.

⁴¹ Information provided to the Committee by Director Wyvill.

An additional problem, the perception in the community that the State of Nebraska has not made a commitment to keep BSDC open into the future, was identified by the employees at BSDC as a contributing circumstance to the difficulties this institution faces in hiring workers in the Beatrice community. When asked about BSDC as an employer in the Beatrice, a number of individuals expressed that members of the Beatrice community regard the future of BSDC as uncertain. This uncertainty has led to a reluctance to make a commitment to work at BSDC when there has been no clear indication by the State of Nebraska that the institution will remain open.

Management

In many ways, the issues regarding management are a mirror image of the concerns expressed by the employees of BSDC. This is certainly true with respect to middle management at BSDC.

The bigger concern, however, for the Committee is not with BSDC middle management. Rather, the greatest concern regarding management of BSDC is with the CEO of the Department of Health and Human Services, the Director of the Division of Developmental Disabilities and the CEO of the Beatrice State Developmental Center.

Ultimately, Beatrice represents a failure of management. Too often the Committee has heard excuses for these failures. Those excuses range from the geographical location of BSDC to past reorganizations of the Nebraska Department of Health and Human Services. In the end, however, these excuses must give way to accountability. Indeed, the Legislature was told that the reason the Nebraska Department of Health and Human Services was reorganized in the first place was to provide accountability. It is the considered judgment of the Committee that accountability of top management must necessarily be measured not by the process employed by management but by the results. Judged by the results, these individuals, however well intentioned, have failed to set BSDC on a proper course. Indeed, the CEO of the Department of Health and Human Services has presided over BSDC at a time when the Department of Justice found that the State violated the civil rights of the residents and CMS decertified the institution and withdrew \$28,000,000 annually in funding. The Director of the Division of Developmental Disabilities and the CEO of the Beatrice State Developmental Center were admittedly not serving in their current capacity at the time of the November 2007 CMS survey and the DOJ inspection. On the other hand, they have been unable to rectify the problems at BSDC notwithstanding the assistance of Liberty Consulting Group, which was paid \$1.5 million to provide a plan for turning BSDC around.

It is not only the failure to properly manage BSDC but the apparent lack of any vision for what BSDC might be for the people of the State of Nebraska in the future. Rather, these individuals who have had frequent contact with the Committee have demonstrated a mentality of “what-do-we-have-to-do-to-get-CMS-off-our-backs” rather than vision and leadership. They have also presided over the deterioration of the culture at BSDC. Witnesses often said that BSDC stood in the 1990’s as an example of a well-run state institution for individuals with developmental disabilities. Witnesses attributed this period during which Nebraska enjoyed a

good reputation nationally to not only a commitment by the State to individuals with developmental disabilities but the presence of management which cared about the residents as well as the staff. This is simply not the case today.⁴²

The Committee does not make this criticism lightly. We are struck by what the necessity of a special investigative legislative committee says about the management of this division of the Department of Health and Human Services. An agency, a department or an institution should operate without the level of dysfunction identified by DOJ and CMS. Indeed, these agencies should not require micromanagement by the legislative branch and the fact that they do demonstrates all too clearly that those in charge are in over their heads.

Those who call BSDC home as well as those who wait in line for services deserve better.

Community-Based Programs

Discussion regarding community-based programs initially presents in the context of moving people from BSDC to community-based programs. The first observation of the Committee with respect to community-based programs relates to the appropriateness of placement of individuals in a community setting. While the United States Supreme Court in *Olmstead* very clearly expressed that the ADA requires placement in the most integrated and least restrictive setting, the admonition calls for the option of placement in a community setting when such a placement is in the best interests of the individual.

It is important to recall that many of the residents at BSDC present a dual diagnosis, which results in significant challenges to appropriate community-based programs. For example, three-fourths of the residents at BSDC have speech and language impairments; almost half are non-ambulatory and two-thirds have a history of seizure disorders, 10% of which are uncontrolled. More significantly, half the residents receive medications to control behavior that would injure themselves or others and 40% have significant behavioral needs requiring behavioral program intervention.⁴³ These statistics demonstrate the challenges with placement in a community setting. It is the opinion of the Committee that the sole criteria for placement into the community is the best interests of the individual and the community to which they will be placed, rather than considerations of cost savings which invite placement where individuals do not receive the services they require or which place the individual or the community at risk with uncontrolled behaviors.

Real issues exist regarding capacity. As the DOJ observed, a barrier to community placements from BSDC is “the lack and/or perceived lack of available community resources, including inadequate community provider expertise and capacity.” The DOJ noted that “the State appears to provide inadequate expertise and support to place individuals and to their providers when behavioral and mental health concerns and crises emerge. The lack of adequate community resources, real or perceived, has the effect of discouraging families and guardians from pursuing community alternatives to BSDC placement.” The result, as expressed by the

⁴² Testimony of Dr. Lee Zlomke, June 23, 2008, page 64, and testimony of Patricia Crawford, August 21, 2008, pages 46 and 47.

⁴³ NAS Report page 15.

DOJ, is that “an unfortunate cycle has been created: community resources are not developed because parents and guardians oppose and the parents and guardians oppose because sufficient community resources have not been developed. The State has not done enough to break this cycle by creating sufficient incentives for community providers to respond to service referral requests and to develop homes and resources to meet the placement needs of BSDC residents.”⁴⁴

The problems with service delivery in the community are more than perception. The DOJ observed: “Problems with service-delivery and monitoring of the community appear to be having a direct, negative impact on the health and welfare of a number of clients with developmental disabilities who live in the Nebraska community system. During our visit, for example, we learned that a number of community clients have experienced significant problems associated with their inadequately addressed behaviors and/or inadequately treated mental illness....It seems clear that the State has not done enough to ensure that adequate behavioral supports and psychiatric care are provided to clients in the community.” The DOJ also observed that the problems in the community-based programs affect BSDC residents: “As referenced above, problems in the community like this have a negative impact on current BSDC residents as well. If the State does not identify and resolve such community problems, certain BSDC residents, who are entitled to adequate and integrated community placements, will not have a viable alternative to ongoing, unduly restrictive care at the BSDC institution.”⁴⁵

To the extent community-based placement is regarded as the panacea for the right sizing of BSDC, identified problems abound. The Committee is aware that there are many competent community-based providers who offer quality services to individuals with developmental disabilities. On the other hand, serious issues relative to capacity and support of community providers exists.

In many ways, the difficulties of BSDC are also present in the community-based provider system. The Committee heard testimony regarding staffing shortages and the lack of properly trained staff with community-based programs. Very clearly, these problems cause difficulties as the State attempts to move people from BSDC to the community. They also present difficulties for those who rely on community-based programs for services and those on the waiting list hoping one day to receive community-based services.

In addition to issues that relate directly to transitioning patients from BSDC to community-based programs, there are deficiencies with oversight in community-based programs that are common to those transitioning from BSDC as well as those currently receiving services in a community-based placement.

Oversight is a two-step process. At first there must be in place proper regulations to govern the providers. Secondly, there must be an adequate number of surveys. In both respects, the State’s community-based provider system falls short.

Where ICF/MR’s are governed by CMS regulations, no corresponding comprehensive regulations govern community-based providers. Certainly no one wants to see regulation for the

⁴⁴ DOJ Report page 35.

⁴⁵ DOJ Report pages 35-36.

sake of regulation. On the other hand, standards such as those employed by CMS are regulations which reflect the standard of care for the treatment of individuals with developmental disabilities.

Not only does Nebraska lack comprehensive regulations for the governance of community-based providers, it also lacks sufficient personnel to inspect or survey the community-based providers. In testimony presented to the Committee (the Licensure Unit of the Division of Public Health of the Nebraska Department of Health and Human Services), which is responsible for surveying community-based providers, indicated that there are four inspectors responsible for surveys of all community-based providers in the State. The consequence of the low number of inspectors means the community-based providers are reviewed once every four or five years rather than annually which is the case for ICF/MR's. This simply is not enough.

Waiting List

While the developmental disability spotlight has most recently been shown on BSDC, a similarly troubling circumstance exists for those on the so-called waiting list. The waiting list is a phrase used to describe those with developmental disabilities who get in line hoping one day the State of Nebraska will provide necessary services. The growing numbers on the waiting list stand as a testament to the consistent neglect shown to the those with developmental disabilities.

Any Nebraskan who has a developmental disability is potentially eligible for services in Nebraska, according to the Developmental Disabilities Services Act. Once their eligibility is determined, a request may be made by the individual or their family and they select a date when they believe services will be necessary for that individual. They are then placed on the Division of Developmental Disabilities Registry. The individual does not go on the waiting list until their date of need has been reached or passed. Individuals on the waiting list were last offered services in 2006.

In contrast to 1997 when Nebraska had only a handful of persons on the waiting list and passed their date of need, as of July 1, 2008, there were 1,865 persons officially waiting for services in Nebraska. Of these, 1,628 were waiting for residential services. In total, there are 2,443 requests for services from these individuals.

Since 2006, there have been two groups of individuals who have received services, those with an emergency need (priority one status) and graduates from Nebraska high schools or those who have turned 21 years of age. Services are authorized on an emergency basis if there is a threat to the health or safety of the individual. If this occurs, the individual is eligible for day or residential services. Those on the waiting list who graduate from a Nebraska high school or turn 21 are currently put at the front of the list and offered day services and service coordination. As a result of a lack of funding, it is rare for an individual in this category to receive residential services. If they have a need for residential services, they are placed on the waiting list.

Nebraska's attrition rate for individuals with developmental disabilities receiving services is approximately 200 per year. The priority one individuals as well as the graduating high school students who received day services annually take up the services vacated by those who leave the

system. The net result is that the number of persons receiving services remains approximately the same while the waiting list grows at a rate of 200 individuals per year.

The waiting list persists notwithstanding the Developmental Disability Services Act which, among other things, provides:

“All persons with developmental disabilities shall receive services and assistance which present opportunities to increase their independent, productivity and integration into the community.”

Neb. Rev. Stat. §83-1,202.01 specifically provides:

“It is the intent of the legislature that the state pursue full funding of community-based developmental disability programs in a reasonable time frame and the legislature commit itself and the state to attaining a goal of providing services to all eligible persons by July 1, 2010.”

In contrast to the stated intent of the Legislature, the goal of providing services to all eligible persons by July 1, 2010 is simply not going to happen. More concerning is that there appears to be no initiative to do anything to address the waiting list other than watch it grow.

The Committee recognizes that LR 156 created a task force specifically assembled to evaluate the waiting list.⁴⁶ In that regard, we appreciate the testimony of Mary Gordon, Director of the Nebraska Planning Council on Developmental Disabilities. Nevertheless, the Committee feels the waiting list issue is so acute and must be part of the State’s priorities as we set a course for providing services to individuals with developmental disabilities that its inclusion in this report was critical.

Future of Developmental Disability Services in Nebraska

In the section which follows, the Committee makes specific recommendations regarding the provision of services to individuals with developmental disabilities by the State of Nebraska. Before providing recommendations, however, the Committee feels compelled to set forth a vision for the future of services to individuals with developmental disabilities in Nebraska.

Very clearly, the current state of Nebraska’s programs for the individuals with developmental disabilities is at a critical point in time. Nevertheless, the Committee feels there are opportunities for Nebraska to return to its place of prominence as a provider of services to individuals with developmental disabilities. This return to prominence will not take place overnight. Nevertheless, a vision for the future of services to individuals with developmental disabilities must necessarily be established so that state government has a roadmap to take us from the place we find ourselves to our return to excellence.

While there are many facets to the problems with delivery of services to the individuals with developmental disabilities, we believe the starting place is with the Beatrice State

⁴⁶ The LR 156 Report has been completed and can be found in the Appendix at “H”.

Developmental Center. The first, and perhaps most simple, step is to recognize that there is a place for BSDC in Nebraska's delivery of services and that a commitment to keep BSDC open must be made both publicly and in reality. In truth, the State of Nebraska does not have an option other than keeping BSDC open. The community-based programs simply lack the capacity and support to absorb the residents at BSDC.

While *Olmstead* very clearly calls for community placement in the appropriate circumstance, the reality is that the needs and behaviors of a certain portion of the population of individuals with developmental disabilities can only be served in an institutional setting. That is certainly the case given the present state of community-based providers. For example, those with serious self-injurious behaviors and those who engage in criminal behavior must necessarily be placed in an institutional setting for the safety of the community as well as the disabled.

Because the Committee believes that BSDC must remain open to provide care for the most challenging of the population of individuals with developmental disabilities, the first priority moving forward must be a retooling of the "recertification strategy." Very clearly, Nebraska finds itself with its back against the wall at BSDC and, as a consequence, there are no other options other than the recertification strategy. This strategy, however, must be retooled. In order for the recertification strategy to carry the day, it is, in the judgment of the Committee, critical that new leadership be put in place and that sufficient resources be devoted to the effort to ensure the highest likelihood of success.

The road map out of the quagmire at BSDC has been provided to the administration. Liberty Consulting (which the State paid \$1.5 million) provided the administration a plan. In addition, the Consent Decree entered into between the State of Nebraska and the Department of Justice has provided the administration with, what the Committee believes, is the clearest and most comprehensive course for turning the problems around at BSDC.

Beyond BSDC's role as provider of services to the most challenging population, BSDC with proper leadership, has the potential to serve as a resource center for community-based providers across the state. The DOJ properly pointed out that the OTS and the ITS programs are fine examples of programs which support community-based providers in dealing with challenging behaviors among their clients. It is the Committee's judgment that BSDC has the potential to serve as a resource in other respects as well. Indeed, the failure to provide community-based providers with necessary support represents one of the most significant deficiencies in the community-based programs. These deficiencies, in turn, frustrate efforts to place BSDC residents in the community and otherwise contribute to difficulties with community placement.

The shortcomings with community-based providers is bigger than the problems it presents to placement of BSDC residents into the most integrated setting. The Committee believes that the second priority in repairing the broken system of delivery of services to individuals with developmental disabilities involves addressing important issues that plague community-based programs. Those issues include developing comprehensive and relevant regulations for providers. A measure must be in place by which provider performance is judged. Those regulations need not necessarily be as comprehensive as the CMS regulations governing

ICF/MR's. On the other hand, regulations must be in place to provide for the safety and habilitation of those in the care of community providers.

It is not enough to develop regulations if the resources are not in place to see that they are followed. The Committee believes that improvement of community-based programs necessarily requires that the Licensure Unit of the Division of Public Health be given adequate staff to perform inspections of facilities where residential and day services are provided.

While the spotlight has been on BSDC over the last several years, the Committee is familiar with incidents taking place in community settings which are fairly characterized as abuse and neglect. For that reason, the Committee's second priority is developing a proper system of oversight for community-based providers. Our failure to do so will result in simply taking our problems from one institution and scattering them across the state.

The third priority for the State of Nebraska must be to improve the capacity of the community-based providers to serve individuals with developmental disabilities. *Olmstead* requires that individuals with developmental disabilities be served in the most integrated setting. In order to accommodate the mandate of the ADA and *Olmstead*, assessments must be undertaken of the residents at BSDC to determine their suitability for community-based placement. As this is done, there must be capacity in the community-based programs for those individuals who choose to accept an accommodation by placement in the community. Increasing capacity is likewise important to those who find themselves on the waiting list.

The fourth priority of the State must be to attend to the needs of those who find themselves on the perpetual waiting list. To date, the administration has justified its neglect of the waiting list by pointing out that developmental disability services is not an entitlement. This may or may not be true. Certainly the Developmental Disability Services Act expresses the intent of the Legislature to provide appropriate services to the population of individuals with developmental disabilities and that is simply not being done at the present time.

The Committee recognizes that capacity and oversight issues in the community-based programs must be addressed before meaningful progress can be made on the waiting list. On the other hand, with proper leadership, and an earnest commitment of resources, the waiting list can and should be reduced to a level where those who are nonpriority one status wait no longer than twelve months for appropriate services.

Ultimately, the delivery of services to individuals with developmental disabilities will require commitment to a model which has at its center the Beatrice State Developmental Center. The State must commit the resources to keep BSDC open so that it may serve those individuals for whom community-based placement simply is not appropriate. BSDC has the potential to serve as a hub or a center of excellence for not just the residents of this institution but those who provide services in community-based settings.

Broad-sweeping statements regarding visions of what BSDC might become and what improvements in the community-based programs might look like are all fine and good. In the end, making any vision a reality requires leadership and the commitment of resources. Indeed,

the lives of those who call BSDC home as well as \$28,000,000 annually in funding from CMS are dependent upon it.

RECOMMENDATIONS

Mindful of the identified concerns as well as the stated priorities, the Committee makes the following recommendations:

1. BSDC

- A. The State must make a commitment to keep BSDC open. BSDC serves an important function in the delivery of services to individuals with developmental disabilities. This institution must be available for placement for those individuals whose needs and/or behaviors cannot be accommodated with community placement. Moreover, the ITS, OTS and Bridges programs serve important roles in providing for a particularly segment of the population of individuals with developmental disabilities as well as a necessary resource for community-based providers.
- B. New leadership is needed not only to provide the recertification strategy with the best chance of success, but to return BSDC to its place of prominence nationally as an integral part of the State's delivery of services to individuals with developmental disabilities.
- C. An independent, comprehensive evaluation should be done by April 1, 2009 of each client at BSDC. The evaluation will provide the foundation for individual treatment plans and will also serve to identify those residents who are suitable for placement in the community.
- D. Follow the terms of the Agreement which are incorporated in the DOJ Consent Decree and accomplish each element of the Agreement in a timely manner.

2. BSDC MANAGERIAL AND STAFFING ISSUES

- A. A complete evaluation of all mid-level management and administrative staff must be completed by April 1, 2009 to ensure these individuals have the necessary skills to be successful.
- B. A comprehensive staff development program must be established by April 1, 2009. This staff development program should be developed with the assistance of resources at institutions of higher learning in the State.
- C. Create an apprenticeship, or internship program, with colleges and universities to assist with the shortages at BSDC. This serves the dual purpose of providing a resource for chronic staff shortages and begins the process of creating a pool of qualified individuals to properly staff BSDC into the future.
- D. A program must be developed and implemented by April 1, 2009 that addresses the cultural changes that are so badly needed at BSDC. We specifically

recommend the assistance of outside consultants with the expertise to set out a plan of correction to change the troubled culture at BSDC.

- E. Review of salaries and benefits by July 1, 2009 for all personnel with a goal for establishing a competitive wage rate for direct care staff as well as professional and managerial positions at BSDC.

3. COMMUNITY-BASED PROGRAMS

- A. Assemble (or re-assemble) a task force to develop appropriate regulations for the performance of community-based providers by May 1, 2009. This task force should be composed of experts in the field to include community-based providers. The findings of DOJ Report clearly reflect that more families will be comfortable with transitions from BSDC to the community-based programs as their level of confidence in the programs improves. We believe proper oversight is an important piece in developing confidence in the community-based placement.
- B. Increase the staff at the Licensure Unit of the Division of Public Health sufficient to provide an annual survey of community-based programs providing day and support services by July 1, 2009.
- C. Develop sufficient capacity in the community-based programs to meet the needs of those who are proper candidates to transition from BSDC as well as those on the waiting list whose needs will be addressed as recommended below.
- D. Establish a task force to review the State's reimbursement formula. It is clear that the reimbursement formula presents a barrier to placement in community-based programs for high needs individuals. This should be completed within one year.

4. WAITING LIST

Provide services for the needs of individuals on the waiting list over the course of four years after which time the waiting list (comprised of people at or past their date of need) includes no one waiting for services longer than twelve months.

5. APPROPRIATION

- A. A budget must be developed for the next four years which reflects the cost to the State to correct the problems at BSDC as well as the community-based programs. This should be done with the assistance of the Legislature's fiscal staff.
- B. The Appropriations Committee of the Legislature should set aside \$28.6 million annually in the appropriation process to provide for the continued funding of BSDC in the event the recertification strategy fails.

6. CONTINUED OVERSIGHT

- A. The LR 283 Committee should be reauthorized at the beginning of the next legislative session. This investigative committee should work with the Health and Human Services Committee to ensure that the terms of the DOJ Consent Decree as well as the recommendations herein are implemented in a timely fashion.
- B. The Task Force as well as the Health and Human Services Committee should receive copies of critical incident reports (both at BSDC and the community-based programs) for as long as the Investigative Committee continues to exist. Thereafter, copies of all critical incident reports shall be provided to the Health and Human Services Committee.

7. PRIVATIZATION OF BSDC

The fact that Mosaic operates three ICF/MR's in the State and has not been decertified by CMS has not been lost on the Committee. It is a source of frustration to the Committee that while BSDC has been decertified and properly criticized by the DOJ, three private ICF/MR's have continued to operate in the State of Nebraska without similar problems. Indeed, one private ICF/MR operates in the City of Beatrice, Nebraska. This frustration has led this Committee to recommend a study to determine the viability of having a private provider operate the Beatrice State Developmental Center. This study would at least provide the State with information necessary to evaluate this option.

8. VOTE OF NO CONFIDENCE

The Committee expresses a vote of no confidence for the CEO of the Department of Health and Human Services, the Director of Developmental Disabilities and the CEO of BSDC.

FINAL THOUGHTS

The very nature of the Committee's assignment necessitates that this report focus on the problems with delivering services to individuals with developmental disabilities, particularly at BSDC. On the other hand, the Committee would be remiss if we did not acknowledge the commitment and dedication of many people who provide care across the state to individuals with developmental disabilities. Our hearings regularly included accounts of people who have committed their lives to care for individuals with a developmental disability. Indeed, families with loved ones at BSDC regularly testified to the commitment and loving care provided by the professionals and direct care staff at BSDC. A similar situation prevails in the community-based programs.

There are many community-based programs which are well run and staffed by caring people doing their best. We wish to acknowledge the hard work and dedication of these people.

Those who have committed their lives to this calling should understand that our concerns are at an institutional level and our recitation of the problems facing the State are not intended to diminish their dedicated service.

ACKNOWLEDGMENTS

The Committee wishes to thank all of those who testified and otherwise offered their experiences and insights into the broad subject of services to individuals with developmental disabilities. Our understanding of the subject matter is a direct result of their efforts for which we are grateful. The Committee also wishes to acknowledge the hard work of Doug Koebernick, Matt Boever, Jeni Bohlmeyer and many other legislative staff who spent countless hours reviewing tens of thousands of pages of documents and providing valuable assistance in the preparation of this report. Lastly, the Committee would like to thank Beth Otto whose service as Committee Clerk was invaluable to the hearing process.

APPENDIX

- A. Legislative Resolution 283
- B. DOJ Report
- C. DOJ Consent Decree
- D. Liberty Healthcare Report
- E. NAS Report
- F. CMS Summary of Surveys
- G. October 8, 2008 Letter from HHS to CMS
- H. Legislative Resolution 156 Task Force Report
- I. BSDC Employee Survey
- J. Transcripts from LR 283 Public Hearings

For a copy of the items listed in the appendix, you may go to the Unicameral's web site at <http://www.nebraskalegislature.gov/reports/committee.php> or contact Senator Steve Lathrop's office (471-2623) for a CD with each of the items.

ONE HUNDREDTH LEGISLATURE

SECOND SESSION

LEGISLATIVE RESOLUTION 283

Introduced by Flood, 19.

The United States Department of Justice issued a report on March 7, 2008, to Governor Heineman detailing the findings from its 2007 investigation of the Beatrice State Developmental Center ("BSDC") pursuant to the Civil Rights of Institutionalized Persons Act, 42 U.S.C. 1997. The department concluded that numerous conditions and practices at BSDC violated the constitutional and federal statutory rights of its residents. In particular, the department found that BSDC failed to provide its residents with adequate: (1) Protection from harm; (2) training and associated behavioral and mental health services; (3) health care, including nutritional and physical management; and (4) discharge planning and placement in the most integrated setting. In its report, the department listed the minimum remedial measures required to protect the constitutional and statutory rights of the BSDC residents, including increasing the number of employees and ensuring that center residents can live and work in the most integrated setting possible. The report specifically expressed grave concerns regarding staffing difficulties at BSDC and the relationship of those staffing concerns to reports of abuse, neglect, and

substandard care.

The Legislature recognizes that it is essential that citizens under the twenty-four-hour care and supervision of the State of Nebraska be provided with qualified care from trained employees. This care is jeopardized when employees are mandated to work overtime for unnecessarily long hours.

In addition to the United States Department of Justice investigation, BSDC has not complied with the care standards set by the federal Centers for Medicare and Medicaid Service for the past eighteen months. Federal funding of the BSDC has continued only because the state has filed an appeal of the federal government's plan to terminate the state's Medicare and Medicaid funding for the facility. The safety, quality of life, and rights of the BSDC residents are of the utmost concern to the State of Nebraska and it is clear the facility has reached a critical point in its ability to care for its residents.

NOW, THEREFORE, BE IT RESOLVED BY THE MEMBERS OF THE ONE HUNDREDTH LEGISLATURE OF NEBRASKA, SECOND SESSION:

1. That the Legislature hereby calls for the Executive Board of the Legislative Council to meet forthwith and appoint a special committee of the Legislature to be known as the Developmental Disabilities Special Investigative Committee of the Legislature. The committee shall consist of seven members of the Legislature appointed by the Executive Board. The committee shall elect a chairperson and vice-chairperson from the membership of

the committee. The Executive Board is hereby authorized to provide the committee with a legal counsel, committee clerk, and other staff as required by the committee from existing legislative staff. The Executive Board is also authorized to hire outside legal counsel, consultants, and investigators as required by the committee. The committee shall be an investigative committee and is hereby authorized to hold hearings and issue subpoenas as is deemed necessary by the committee.

2. The Developmental Disabilities Special Investigative Committee of the Legislature is hereby authorized to study the quality of care and related staffing issues at the Beatrice State Developmental Center. The committee shall also investigate the placement and quality of care statewide for the developmentally disabled in Nebraska, including the determination of whether adequate funding and capacity exists for persons to be served in the community, options for service provisions for current residents of the Beatrice State Developmental Center at other twenty-four-hour care facilities in the state, and the staffing practices at twenty-four-hour care facilities and the relationship of those practices to the quality of care provided to the developmentally disabled. The committee shall also study the Department of Health and Human Services with respect to such facilities, including how and why services to the developmentally disabled were permitted to decline to the current level as documented by the United States Department of Justice report.

LR 283

LR 283

The committee shall utilize existing studies and reports and legislation developed to address the current conditions. The committee shall not be limited to such studies, reports, or legislation. The committee shall issue a report with its findings and recommendations to the Legislature no later than December 15, 2008.



U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20530

March 7, 2008

The Honorable Dave Heineman
Governor of Nebraska
Office of the Governor
P.O. Box 94848
Lincoln, NE 68509-4848

Re: CRIPA Investigation of the Beatrice State Developmental Center,
Beatrice, Nebraska

Dear Governor Heineman:

I am writing to report the findings of the Civil Rights Division's investigation of conditions and practices at the Beatrice State Developmental Center ("BSDC"), in Beatrice, Nebraska. On May 29, 2007, we notified you that we were initiating an investigation of BSDC pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. CRIPA gives the Department of Justice authority to seek a remedy for a pattern and practice of conduct that violates the constitutional or federal statutory rights of persons with developmental disabilities who are served in public institutions.

On September 6, 2007, we conducted an initial walk-through of BSDC. From October 15-19, 2007, we conducted a more in-depth, on-site review of BSDC with expert consultants in the areas of protection from harm, training and behavioral services, psychiatry, health care, and nutritional and physical management.¹ In conducting our on-site investigation, we interviewed administrators, professionals, staff, and residents. We observed residents in a variety of settings, including on their living units, at activity areas, and during meals. Before, during, and after our visit, we reviewed a wide range of documents, including policies, procedures, medical records, and other documents related to the care and treatment of dozens of BSDC residents. At the end of the tour, consistent with our pledge of transparency and to provide technical assistance where appropriate regarding our investigatory findings, we provided an exit presentation to convey our preliminary findings in each area to State counsel and to facility and State officials.

¹ On October 14, 2007, we conducted a brief on-site inspection of the Bridges facility, a BSDC-affiliated program for about a dozen persons with developmental disabilities, located in Hastings, Nebraska.

We would like to express our appreciation to the BSDC administrators, professionals, and staff and to the State officials, especially Christine Peterson, Chief Executive Officer of the Nebraska Department of Health and Human Services, and John Wyvill, Director of the Department's Division of Developmental Disabilities, for their assistance, cooperation, professionalism, and courtesy throughout our investigation. We hope to continue to work with the State and BSDC officials in the same cooperative manner going forward.

Consistent with our statutory obligations under CRIPA, I now write to advise you formally of the findings of our investigation, the facts supporting them, and the minimum remedial steps that are necessary to remedy the deficiencies set forth below. 42 U.S.C. § 1997b(a). We have concluded that numerous conditions and practices at BSDC violate the constitutional and federal statutory rights of its residents. In particular, we find that BSDC fails to provide its residents with adequate: (A) protection from harm; (B) training and associated behavioral and mental health services; (C) health care, including nutritional and physical management; and (D) discharge planning and placement in the most integrated setting. See Youngberg v. Romeo, 457 U.S. 307 (1982); Title XIX of the Social Security Act, 42 U.S.C. § 1396; 42 C.F.R. Part 483, Subpart I (Medicaid Program Provisions); Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132 *et seq.*; 28 C.F.R. § 35.130(d); see also Olmstead v. L.C., 527 U.S. 581 (1999).

I. BACKGROUND

BSDC is a State-owned and -operated residential facility for persons with developmental disabilities such as mental retardation, cerebral palsy, and autism. At the time of our initial visit in September 2007, BSDC housed a total of 333 residents; the ages of the residents ranged from 14 to 85. There were 15 residents aged 22-years-old or younger; there were 26 residents aged 65-years-old or older.

BSDC residents live in approximately 25 living units spread across the facility's campus. At the time of our visit, about six residents resided primarily in the BSDC acute care unit. In addition, there is an eight-bed residential program on campus called the Intensive Treatment Services ("ITS") unit that admits, on a short-term basis, persons with developmental disabilities who are experiencing temporary difficulties in a home or other community placement. The ITS strives to provide specialized and dedicated treatment and supports for these individuals so that they may return to the community as soon as possible. At the time of our visit, eight persons resided in the ITS.

The Bridges facility is a BSDC-affiliated residential program, located on a separate campus in Hastings, Nebraska. This program treats persons with severe behavioral problems and/or a dual diagnosis of mental retardation and mental illness. The Bridges is a more restrictive residential facility because the individuals served there typically have been involved in serious incidents that led to the involvement of law enforcement. Although it has a bed capacity of 14, at the time of our visit, Bridges served 11 persons with developmental disabilities.

The intellectual abilities of the BSDC residents are varied. The diagnoses of BSDC residents with mental retardation range from mild to profound. The residents possess diverse abilities and functional levels. Some residents require more staffing supports to meet their daily needs, while others are much more independent and capable of meeting their own needs. Many of the residents have swallowing disorders, seizure disorders, ambulation issues, or other health care needs. A significant portion of the BSDC population is medically complex and requires assistance at mealtimes and other frequent monitoring.

There are a number of residents at the facility who have developed maladaptive behaviors, such as self-injurious behavior or aggression. Indeed, almost half of the residents exhibit physical aggression of some sort. At the time of our visit, the facility reported that over 175 BSDC residents had a behavior program and that these programs typically included some form of restrictive component, such as 4-point and 5-point restraints used on residents in beds. In the year prior to our visit, dozens of BSDC residents were subjected to highly restrictive interventions, often on multiple occasions, sometimes for prolonged periods of time. About half of the BSDC residents have been diagnosed as having mental illness, and all but a handful of these residents were receiving one or more psychotropic medications.

II. FINDINGS

A. PROTECTION FROM HARM

The Supreme Court has established that persons with developmental disabilities who reside in state institutions have a "constitutionally protected liberty interest in safety." Youngberg v. Romeo, 457 U.S. at 318. The Court held that the state "has the unquestioned duty to provide reasonable safety for all residents" within the institution. Id. at 324. However, the state fails to protect BSDC residents from harm and risk of harm and to provide them with a reasonably safe living environment.²

² Consistent with our findings here, the Centers for Medicare and Medicaid Services ("CMS") within the United States Department of Health and Human Services has found a number of problems with regard to unsafe conditions and other deficient practices at BSDC in recent years. CMS is a federal agency that is independent from the Department of Justice. On September 29, 2006, CMS conducted a full federal survey of the facility and found numerous deficiencies, including three Immediate Jeopardy citations (the most serious), and seven out of eight conditions of Medicaid participation outstanding. A follow-up survey in April 2007 revealed ongoing deficiencies, including an Immediate Jeopardy citation for inadequate protection of residents, inadequate dental services, and failure to provide adequate food service equipment. A second follow-up survey from October 30 to November 7, 2007, produced an Immediate Jeopardy citation related to substantiated physical abuse allegations, as well as a string of other deficiencies. Ongoing deficiencies imperil the continued distribution of Medicaid funding to the State to provide services for BSDC residents.

BSDC residents are subjected to abuse and neglect and suffer a high number of incidents that often result in injuries or other poor outcomes. We found consistent patterns of staff actions that often subjected residents to repeated preventable injury. Resolution of problems is hampered by concerns associated with BSDC's incident reporting and investigation system.

1. Abuse and Neglect of Residents

Our safety consultant concluded that the nature of many abuse and neglect allegations, and the frequency with which they are made, suggests a "cultural undercurrent that betrays human decency at the most fundamental levels ... basic human dignities are violated with considerable regularity" at BSDC.

For the period between October 1, 2006 and October 16, 2007, the BSDC client abuse, neglect, and exploitation log reveals approximately 200 incidents at the facility that in some way involved an allegation of abuse and/or neglect of residents. Facility investigators substantiated the allegation of abuse or neglect, at least in part, in over half of these cases. Other BSDC documents reveal that in 2007 alone, through the end of September, there were approximately 141 allegations of abuse and/or neglect of residents, with 52 of these allegations substantiated by internal investigators. Last year, through the third quarter of 2007, the facility reported that 185 employees had been suspended due to substantiated abuse or neglect of residents; many of these employees later were either terminated or resigned.

We highlight below a few recent examples where internal BSDC investigations substantiated abuse or neglect allegations, demonstrating, in part, the facility's failure to protect its residents from harm.

a. *Abuse*

- BSDC investigators substantiated mental abuse of resident WC³ after concluding that staff engaged WC in a "game" of what could be called "canine catch" in August 2007. This involved staff tossing WC's pop bottle across the room, instructing the resident to retrieve or "fetch" the bottle, and then return it. After repeating this "game" at least twice, a staffer was observed hiding the bottle behind her back while motioning WC across the room to find the bottle. Not realizing that the staffer had the bottle, WC ran around the room aimlessly searching for it.
- BSDC investigators substantiated physical abuse where a direct care staff worker injured resident VB at the gym. In June 2007, the staff worker pushed her foot down "with force" on the forearm of the resident, who was touching an outlet. As a result of the

³ In order to protect the identity of residents, we use coded initials throughout this letter. We will transmit separately a schedule cross-referencing the coded initials with the actual names of the residents.

incident, VB suffered severe lacerations on his index finger and down the center of his middle finger through the flexor tendon. The resident had to be transferred to Lincoln for surgery to repair the lacerations. At the time of the investigation, it was unclear whether he would ever regain the full use of his middle finger.

- BSDC investigators substantiated both mental and physical abuse of resident UA, who requires enhanced staffing to meet his needs. In June 2007, a direct care staff worker began to taunt and upset UA while playing a board game. After the resident reached out in frustration, the staffer retaliated by shoving UA and knocking him to the floor, causing a purple bruise to the resident's right elbow.
- BSDC investigators substantiated both physical and mental abuse where, in April 2007, a male staff worker "slammed" resident TW into a wall for pretending to take a female staff worker's lunch item. After the push, TW became sad, went to the bathroom, and cried. TW said the altercation "knocked the wind out" of him. BSDC confirmed three prior allegations of physical abuse of this resident by the same staff worker in the prior nine months.
- BSDC investigators substantiated both verbal and physical abuse by a staff worker against resident SV, who uses a wheelchair. In April 2007, the staff worker observed SV start to spit out medicine she had given to him. The staff worker used demeaning names to address the resident and then held the resident's head against the headrest on his wheelchair, forcing a spoon into his mouth; after that, she forcibly held a washcloth across SV's mouth, trying to make him swallow. According to an eyewitness, this situation continued for 10 minutes.
- BSDC investigators substantiated verbal abuse of resident RU by a staffer in June 2007. While taking a resident's blood sugar reading nearby, a nurse overheard a staffer talking to RU in the adjacent bathroom. The nurse reported that the staff worker verbally abused RU while he was bathing, saying: "God damn it, don't you know how to take a bath?" As the resident began to cry, the staffer then said: "So now you think you are going to cry like a b__ch and that is not going to help you out one bit. Let's get this done."
- BSDC investigators substantiated abuse of a 20-year-old female resident, QT, by a male staff worker who was reported to be "obsessed" with her. In November 2006, the male staffer shaved the pubic area of the young female resident. Other staff workers regarded this as inappropriate, yet this incident was not reported for five days.
- In February 2007, an internet website moderator alerted BSDC officials to a web journal, published by a new staff member, that identified both staff and residents, described unauthorized confinement of one resident in a tightly-wrapped comforter ostensibly to prevent movement, and the stated desire of one staffer "to kill" a resident due to frustration. The blogger also alleged that another staff worker sat on a resident "to calm

[the resident] . . . down,” and that a senior staffer told the journal writer that “you have to be a “b\ch” to the clients for them to know you’re in charge.” BSDC investigators found that these acts and the publication of such information constituted abuse and neglect of the residents.⁴

In September 2007, resident PS suffered a spiral fracture of his lower leg. Spiral fractures are typically an indication of purposeful twisting and a marker for possible abuse. However, the facility did not list a cause of the injury or a possible witness to the injury. Indeed, the facility categorizes a large number of incidents/injuries among BSDC residents as of “unknown” origin. In general, a significant number of unknown injuries at an institution suggests an unsafe environment and one where supervision is inadequate to protect residents from harm; at worst, it reveals hidden abuse. At BSDC, internal documents reveal that, between January 1, 2007 and September 30, 2007, there were at least 1,126 incidents/injuries of unknown cause, representing over one-fourth of all incidents recorded during that period.

b. *Neglect*

- BSDC investigators substantiated neglect by a direct care worker who, in August 2007, failed to bathe, check, change diapers, or re-position six residents assigned to her care; instead, BSDC investigators found that the staffer watched television and slept during her work shift.
- BSDC investigators substantiated neglect where, in August 2007, four staff workers in one unit failed to check or change resident OR for four-and-a-half hours. During that time, none of the staff re-positioned the resident, interacted with him, completed his treatments, or conducted his programs. The staff of the next shift discovered OR to be soiled and completely soaked in urine, through his clothes.
- BSDC investigators substantiated neglect where, in July 2007, two staffers had placed resident NQ in her bed for a nap and then left with four other residents for a trip to a softball game. The resident, who should have been checked and changed every two hours by staff on duty, was discovered five hours later still in her bed in the same attire as before, with her clothes and bedding soaked in urine.
- BSDC investigators substantiated neglect after a BSDC housekeeper discovered, in June 2007, that resident MP had been left in her bed, alone in the building for at least 30 minutes, while the unit staff and other residents were away at activities across campus.

⁴ During our on-site tour, one of our expert consultants observed an incident that later may have been substantiated as abuse by BSDC officials. Specifically, our consultant observed a staff member physically preventing a resident from independently moving his wheelchair; she also observed the staff member yelling at the resident to keep away from a table where other residents were eating. Our consultant immediately alerted BSDC officials of the incident.

The investigation describes a chaotic scene on the living unit where residents were counted and miscounted by staff unfamiliar with them.

- BSDC investigators substantiated neglect where, in June 2007, a direct care staff worker improperly cared for resident LO whose ileostomy bag⁵ had come open. The staffer, untrained in this type of care, merely took the resident to the bathroom, placed him on the toilet, and left him there alone. The nurse who came by 20-30 minutes later to replace the bag noted that the direct care staff worker was watching television. She found LO still on the toilet with feces on his body, his clothing, and on the bathroom floor.
- BSDC investigators substantiated neglect where, in May 2007, resident KN, requiring close 1:1 supervision within a distance of five feet, eloped from his BSDC living unit; he was later found at an apartment complex away from the campus. Staff on the unit were unaware that this particular resident required 1:1 staffing.
- In April 2007, one staff worker was left alone on a living unit to care for 16 residents. Resident YM, who requires supervision within visual range, eloped from the building and was later found in a campus driveway with one of his wheelchair's wheels caught on the curb. BSDC's investigation was unable to determine for how long YM had been outside the building before staff noticed him. BSDC investigators substantiated that the assigned staff worker had neglected the resident. The practice of leaving residents alone and unsupervised was found in a number of other abuse and neglect investigations as well. In addition to lapses in supervision, BSDC residents also sustained injuries due to staff being unaware of residents' support needs.
- BSDC investigators substantiated neglect where, in April 2007, resident KN may have sexually assaulted another resident who was to have been closely supervised. The victim's program required assigned facility staff to check on him at least once every 30 minutes. However, BSDC investigators determined that no such checks had been done, concluding: "[h]ad the checks been done, [staff] would have interrupted the incident or prevented it."
- In early March 2007, within a 24-hour period, a BSDC staff worker twice failed to report that she saw resident IL chewing on pieces of his colostomy bag. In one of these incidents, the resident had smeared feces on his face, body, and mouth. Although the neglect charge was substantiated against this staff person, she remained employed at BSDC and continued to be assigned responsibility for IL's support and care. Less than two months later, the same staff person was again found negligent in caring for IL.

⁵ An ileostomy bag is a plastic or latex bag attached to the body for collection of urine or fecal material after an ileostomy or cystoplasty.

2. Incidents and Injuries

We found that BSDC's risk management practices fail to identify residents' risks and fail to implement preventive strategies necessary to keep residents from harm and risk of harm. Indeed, BSDC documents reveal that residents regularly experience harm and risk of harm in their day-to-day lives. Facility records indicate that for the period between September 1, 2006 and October 12, 2007, there were thousands of separate recorded incidents involving residents at BSDC. The facility produced a 240-page list of what we estimate to be over six thousand separate incidents during this period. Other BSDC documents reveal 4,328 separate resident incidents at BSDC in 2007 alone (through September).

While some of these incidents were relatively minor with no injury to residents, others were very serious and produced grave injuries. Through the end of September 2007, BSDC documented 3,306 incidents where there was at least a "minor" injury to residents. This works out to be an average of about 367 resident injuries per month, or about 85 resident injuries per week, or about 12 resident injuries per day at BSDC. During the period between September 1, 2006 and October 12, 2007, BSDC identified about 150 incidents as more serious or severe than a "minor" injury. Serious injuries include fractures, lacerations, bites, and choking incidents.

Some residents have been involved in multiple incidents. Through December 30, BSDC reported an average of 35 residents per quarter who were involved in 10 or more incidents/injuries last year. Residents GJ, FI, EH, and DG all averaged more than 20 incidents/injuries per quarter through September 2007.

a. *Resident Aggression*

A large number of resident-to-resident incidents at BSDC stem from resident aggression. From September 1, 2006 through October 15, 2007, BSDC identified over 100 different residents who were characterized as "aggressors" in well over 500 separate incidents. In 2007 alone, through September, BSDC identified resident aggression as the probable cause of 217 separate incidents that produced at least a "minor" injury. The injuries of aggression to victim residents, include lacerations, bite marks, scratches, scrapes, bruises, and abrasions.

Some of the incidents have been serious. For example, in September 2006, resident CF attacked her roommate, HK, with a four-inch steak knife. HK sustained a laceration to her left temple and upper arm, and a stab wound to her lower left back. After the attack, the victim was "crying and in near hysterics." CF told staff that "voices" made her attack HK and that she wanted to kill her roommate and "everyone on the living unit." On the Monday prior to this incident, CF's mother reported that a knife of similar description was missing from her home after CF's visit. The internal BSDC investigation does not indicate whether staff searched CF's room for the knife after the home visit and prior to the stabbing incident. In spite of this, BSDC made no finding of neglect. In a separate incident a month later, resident BE alleged that his roommate, TO, had sexually assaulted him in the bathroom. BE suffered injuries to his neck and

lip. However, no physical evidence of a sexual assault was found. The internal BSDC investigation did not reach a definitive conclusion as to what happened. BSDC made no findings as to abuse or neglect with regard to this incident.

BSDC records reveal that resident aggression incidents/injuries appear to be concentrated on certain units, such as 104K and 408S.⁶ Lack of adequate staff supervision, environmental and safety concerns, as well as a failure to provide adequate behavior and mental health supports all contribute to an increased risk of harm for many residents on a day-to-day basis.

b. *Fractures and Falls*

In the year before our visit, a number of BSDC residents suffered fractures, including fractures of the leg, hip, knee, ankle, toe, clavicle, shoulder, arm, hand, finger, and nose. Many of the fractures were quite serious, requiring the intervention of an orthopedic surgeon. It is of concern that about half the time, BSDC did not know how the fracture happened. We set forth below a few examples of residents who suffered fractures in the months prior to our visit.

- In April 2007, staff noted a bruise on resident AD's arm while preparing the resident for a bath. Later it was determined that AD had suffered a fracture of the right humerus. Although a physician concluded that the injury was the result of blunt force trauma, it remains undetermined how and where the fracture occurred.
- In March 2007, resident LA refused to bear weight on his left leg. The next day, staff observed bruising to the resident's ankle, but an x-ray showed no fracture. A subsequent x-ray, done a week later, showed an oblique fracture through the left distal fibula. The cause of the fracture is undetermined.
- In January 2007, while attempting to transfer resident KZ from her wheelchair to her bed, a BSDC staff worker was unable to lift the resident onto the bed, and instead lowered her to the floor. The following day, other staff noticed a "pop and crackling" sound as they tried to dress KZ. Subsequent medical examination identified a fracture to the resident's lower leg.

Resident fractures are often caused by falls. Indeed, there is a significant and serious pattern of resident falls at BSDC, numbering more than 1,000 since September 2006. The facility has documented repeated falls by a number of residents: GJ - 50 falls, FI - 45 falls, EH - 43 falls, ND - 25 falls, DG - 25 falls, OE - 24 falls, and PF - 23 falls. The high frequency of falls places these and other similarly situated residents at great risk of harm. Yet, too often, BSDC has failed to develop effective safeguards to reduce the frequency of resident falls. Some falls have resulted in significant harm to residents. For example:

⁶ Units 104K and 408S are just two of several units that house residents with developmental disabilities who also have behavioral problems and/or mental illness.

- In late July, 2007, staff noted a significant purple bruise to resident QG's left shoulder during bathing. Examination revealed a fracture of the left humerus. Although medical staff felt the injury was caused "by blunt force trauma," BSDC concluded that the injury was accidental, possibly from an unwitnessed fall.
- In July 2007, resident MC fell, suffering what appeared to be a fracture of his left clavicle; staff noted significant purple bruising on his shoulder.
- In June 2007, resident BF, known to have osteoporosis, fell while approaching the bathroom, suffering a left hip fracture. In response to BF's numerous falls, the BSDC Incident Review Team often recommended "no further action necessary." This response is similar to that given to other residents who fall regularly or are at risk of falling.

Our investigation revealed a pattern in which numerous residents suffered multiple falls, yet were not identified as individuals at-risk for falling. As a result, the facility failed to provide adequate preventive interventions. For example:

- Resident UL, admitted in August 2006, suffered injuries from falls three times within her first month in residence at BSDC. Despite her recurring falls, she was not identified as being at-risk for falls and protective measures were not implemented. Within 75 days of her admission, she suffered her fifth fall, sustaining a fracture to her right thighbone (femur). This fracture required surgery to implant a fixture pin. The investigation of this fall failed to identify a pattern and UL continued to fall in subsequent months.
- Resident PF fell at least 23 times between September 2006 and June 2007, but was not identified as at-risk for falling by BSDC. One of his falls caused a laceration to his head which required staples to close. In early 2007, PF suffered a fractured finger on his left hand. As of mid-October 2007, BSDC had still failed to identify PF as at-risk for falls.
- Resident DW, referenced above, began to fall with increasing frequency around October 2006. She fell about a dozen times from October 2006 to July 2007. Despite this, as of mid-October 2007, BSDC had still failed to identify DW as at-risk for falls.

There are many other residents who have incurred serious injuries from falls, and yet, are not identified by BSDC as being at-risk of falling, including: QH, KZ, BF, RI, SJ, TK, and NQ. BSDC's failure to identify individuals' risks and implement preventive strategies places residents at significant and continuing risk of harm.

c. Lacerations

A large number of BSDC residents have suffered lacerations, many of which are deep and serious. The facility identified about four dozen residents who, during the year before our visit, had suffered a laceration that required sutures, staples, clips, or dermabond to close the injury.

About 95 percent of the serious lacerations involved injury to the face or head. Some of the residents suffered multiple deep lacerations; for example, throughout the year, resident DG suffered separate deep injuries near her right eyebrow, her left eyebrow, the bridge of her nose, and her upper nose. Most of the resident injuries appear to occur due to inadequately addressed behaviors – sometimes from self-injury, and sometimes from the unchecked aggression of another resident. Other causes of lacerations include falls, environmental factors, and seizures.

d. *Choking Risks*

Many BSDC residents have medical conditions that seriously complicate the swallowing and digesting of their food and beverages. We uncovered several instances in which staff failed to adequately protect residents from consuming food or fluids that could cause them serious harm. For example:

- Resident VM, fed via stomach tube, is assigned enhanced supervision due to her high risk for aspiration. Despite this, in April 2007, VM's staff left her alone in the dayroom, where she drank a cup of liquid set out for another resident. This was the fifth time since 2004 that the resident has consumed an edible or liquid that placed her at serious risk of harm. The subsequent review of this incident noted that, "[the resident's] consumption of food could cause serious airway blockage, anoxia, and death; her consumption of liquids could lead to aspiration of the contents into her lungs. It is imperative that [she] receive the proper supervision to guard against her ingestion of food or liquid." Within weeks, in July 2007, staff found the same resident in the dining area chewing corn chips. BSDC found that an on-call staff worker in that instance neglected her by leaving his assignment before arranging for her supervision. BSDC's repeated failure to protect VM places her at serious risk.
- BSDC investigators confirmed neglect where, in July 2007, resident WN, also fed by a stomach tube and not allowed food or drink due to the risk of aspiration, walked over to a table in his living unit and drank tea left there. No specific staff had been assigned to supervise this resident at the time despite his need for enhanced supervision. The investigative report also noted a prior incident on May 6, 2007, where this resident drank grape juice, which also placed him at serious risk for aspiration.

In addition, a couple of other residents have ingested inedible objects that posed great risk to the resident; resident OK swallowed a push-pin tack, and resident CF may have swallowed a "train" game piece.

3. Incident Reporting, Investigations, and Preventive Measures

a. *Incidents*

We identified a number of problems with the facility's incident management system. BSDC's policies and procedures related to reporting and categorizing incidents are disjointed, uncoordinated, and confusing. As a result, incidents are not consistently categorized at BSDC. During our visit, we learned that multiple databases at BSDC hold information about harm to residents. We learned from a variety of sources that all incidents are not tracked in the same database. For example, the Quality Indicator Report that should contain accurate information, and is to be reviewed quarterly, does not include hundreds of falls experienced by residents and documented elsewhere. We also found that important incident reports sometimes are not accounted for in the tracking system. We identified instances where staff failed to report incidents in a timely manner. This raises concerns about whether other important incidents are being reported on time or at all. As a result, we do not have confidence that the incident information recorded and reported at BSDC accurately reflects all of the reportable incidents that actually occur at the facility. Given these failures, the incident and injury numbers we set forth above may, in fact, under-represent the harm that has actually occurred at the facility. This also makes the tracking and trending of such incidents unreliable, which further impairs the facility's ability to develop and implement individual or systemic remedial measures. It is essential that management staff have reliable data sources that will allow them to review trends and analyze and address the underlying causes of all injuries.

The BSDC Incident Review Team (IRT), chaired by the acting director of quality management, reviews all incidents that have occurred within the previous 24 hours. The intent behind this effort is commendable. However, there are some concerns. For example, the residents' interdisciplinary team members are notably missing from this review process. Moreover, although the IRT serves the function of keeping facility management informed of sentinel events, this process actually delays the interdisciplinary teams' response to events and shifts the accountability for resident safety from the QMRP and interdisciplinary team to the facility management staff. Since the IRT does not necessarily possess in-depth knowledge of the residents' status, it is ultimately dependent on the team to determine intervention strategies to reduce risk.

The facility's lack of effective risk management and incident management practices places residents at risk of serious harm. It is imperative that the facility establish both preventive and responsive processes that proactively work to reduce and eliminate harm.

b. *Investigations*

We found some positive aspects with regard to recently-begun remedial efforts in the area of internal investigations. BSDC has demonstrated its intent to broaden the scope of its investigative process. Based on the volume of investigations from 2006 to 2007, the facility has

increased the number of incidents it formally investigates. In addition, BSDC's investigative unit has made considerable improvements in identifying systemic and ancillary issues relevant to investigations. Systemic issues are more consistently identified with meaningful corrective actions assigned.

Nonetheless, the facility must continue to correct deficiencies and improve the quality of its investigations in order to reach minimally accepted standards of practice. We found that there were significant delays in reporting some allegations of abuse and neglect. Similarly, there were delays in providing relevant documents to the investigator in some cases. Investigators did not consistently secure evidentiary materials. Investigations often lack necessary components. For example, some investigations failed to: reconcile evidence appropriately, develop a chronology of the event, identify involved personnel, include interviews of all relevant staff and residents who may have information about the incident in question, and determine the cause of serious incidents. Many investigations fail to develop a reasoned analysis of what actually happened and who was responsible. In some instances, the investigative report does not discuss how information that was gathered was utilized to draw conclusions. We also found instances where investigations were filled with speculative commentary by both staff and investigators, apparently set forth to rationalize why a more thorough review of the allegation was not necessary. A speculative approach and lack of objectivity is a significant departure from minimally acceptable standards of practice.

Inadequate investigations make it difficult for the facility to identify, develop, and implement corrective measures to eliminate preventable risks to residents. BSDC documents reveal that many corrective measures that were supposed to be implemented post-investigation to prevent future incidents are not being implemented and monitored in a timely or adequate manner. Such failures place residents at ongoing risk of harm. Subsequent investigations indicate recurrent issues that have not been resolved. Our safety consultant concluded that BSDC is not monitoring the effectiveness of corrective actions with any regularity, and as a result, "recurring issues are illuminated through investigations though they rarely appear resolved."

4. Staffing Concerns

Many of the deficiencies at BSDC with regard to safety are linked to staffing difficulties. Our safety consultant characterized the BSDC workforce as "wrought with exhaustion and discontent." She reported that some employees pleaded for help in order to acquire adequate staffing assistance for the health and welfare of the residents. During our visit, BSDC staff expressed concerns about being assigned to work with residents without being trained on how to properly support and care for them. They also told us about their concerns related to unsafe working conditions due to severe staff shortages, employee exhaustion, lack of adequate training, and disgruntled co-workers.

The facility faces substantial and ongoing struggles in hiring and retaining competent staff, maintaining acceptable individual-to-employee staffing ratios, and providing adequate time off to full-time employees. During the week of our visit in October 2007, the facility had vacancies in 117 of 411 direct care staff positions. In addition to these, there were vacancies for a physician, six nurses, a nurse supervisor, a physical therapist, two team leaders, and two compliance specialists. Many of these positions had been unfilled for months.

Given the large number of staff vacancies, the facility has relied heavily on requiring current staff to work overtime. BSDC records reveal that direct care staff have been working overtime – sometimes on double shifts – for more than a year now. The facility used 10,219 hours of overtime in September 2007, and 14,490 hours in August 2007. These levels are reduced from the January 2007 high of almost 20,000 overtime hours in the month. For the period September 2006 through September 2007, the facility spent \$3.6 million on overtime reimbursement. Overtime is often mandatory for current BSDC staff. We spoke to numerous staff who related their concerns about having to work multiple double-shifts (16 consecutive hours) within a single week to provide care to residents. Many staff workers expressed their weariness at being “frozen,” or required to stay for additional shifts or risk disciplinary action for failure to fulfill overtime requirements.

Even with staff working so many additional hours, we learned that the use of overtime is often not enough to meet staffing needs. As a result, the facility maintains a roster of 180 Developmental Technician I employees who are described as “on-call” staff. These employees (including staff as young as 16 years of age) are assigned to work with residents across the campus as needed. However, many of these on-call staff are unfamiliar with the residents they are assigned to serve. Although all staff, including the on-call staff, are supposed to be familiar with the needs and individualized plans of the residents on their assigned units, we met staff workers who were unable to tell us that information, much less implement the plans.

In addition to the large number of staff vacancies, we found a lack of adequate oversight of staff. We uncovered several instances where staff were found asleep while on duty and where staff were found to be playing cards or watching television when they should have been providing services to residents. One supervisor told us that she was new to her area and did not know which staff were assigned to her area from day-to-day. The chaotic staff environment at BSDC fragments care to residents and places them at risk of additional harm.

Needless to say, the demands of current BSDC staffing practices place both emotional and physical stress on the staff that may lead to an environment that is more conducive to abuse, neglect, and mistreatment. At the very least, tired and over-worked staff will be less likely to take the initiative and responsibility necessary to provide residents with the programming, care, and treatment they need, especially if the residents have difficult behaviors or complex health care needs. BSDC needs to take deliberate action to improve this situation. Failure to do so will continue the current environment that is conducive to abuse, neglect, and inadequate care.

5. Documentation

Clinical records at BSDC do not consistently provide an accurate account of residents' needs. Moreover, there is inconsistency among the tools utilized at BSDC to provide staff with information on the current intervention strategies to protect individuals from harm. We found that there was conflicting information on such tools as supervision cards, individualized program plans, and mental health treatment plans.

We also found that outcome data for interventions was often inaccurate. Record reviews at BSDC revealed significant discrepancies between unit and clinical data, as well as a general inconsistency in maintaining data. Because this data is to be used in clinical decision-making, the health and well-being of individuals is placed at significant risk when clinical records and data reports contain errors, discrepancies, and inconsistencies.

BSDC is currently making efforts to form committees to better analyze outcome data. While this is a worthwhile effort, it is only one element of a complete quality assurance system. Quality assurance needs to be more than a department at BSDC; it needs to be a deliberate and ongoing practice at the facility.

B. TRAINING AND BEHAVIORAL SERVICES, RESTRAINTS, AND PSYCHIATRIC CARE

The Supreme Court has concluded that for persons with developmental disabilities residing in state institutions, there is a constitutional right to "minimally adequate training." Youngberg v. Romco, 457 U.S. at 322. Specifically, "the minimally adequate training required by the Constitution is such training as may be reasonable in light of [the institutionalized person's] liberty interests in safety and freedom from unreasonable restraints." Id. and at 319 ("respondent's liberty interests require the State to provide minimally adequate or reasonable training to ensure safety and freedom from undue restraint").

1. Resident Behaviors and Behavior Programs

Dozens of residents at BSDC have behavior problems and need training and associated behavioral services. According to facility documents, as of August 31, 2007, there were 151 residents with physical aggression, 68 residents with verbal aggression, 41 residents with non-verbal/physical aggression, and 74 with self-injurious behavior. Some residents exhibit multiple behavior problems; 34 residents are listed with three of these behaviors and 15 residents are listed with all four behaviors.

As of September 4, 2007, the facility reports that approximately 187 BSDC residents (including the 11 Bridges residents) with behavior problems receive training and associated psychological and behavioral services through a formal behavior program. Generally accepted practice, as well as BSDC policy, mandates that behavior programs are to provide a consistent,

individualized, and effective approach to reduce or eliminate inappropriate behaviors. In spite of this, BSDC fails to provide training and services that are adequate and appropriate to meet the needs of these residents. This deficiency contributes to poor resident outcomes, including poor progress in treating problem behaviors, increased risk for highly restrictive interventions, increased risk for injury and abuse, and decreased opportunities for placement in the most integrated setting. Inadequate training and psychological services are contributing factors to many of the incidents and injuries discussed above, which often stem from residents' inadequately addressed problem behaviors, such as physical aggression, verbal aggression, self-injurious behavior, or "pica" (ingesting inedible objects).

BSDC behavior programs are typically well-developed, often rather lengthy, and generally follow a consistent format. Nonetheless, the programs often do not effectively address residents' often difficult behavior problems. With regard to behavioral assessments, BSDC relies too heavily on a brief questionnaire screening tool when a more extensive observational analysis of the behavior problem is often warranted to verify functional behavioral antecedents and lead to appropriate treatment options and follow-up services and supports. This is especially true in complex cases where subtleties may be missed and behavioral intervention may be misguided. Appropriate observational analysis is even more important, given that BSDC quality assurance documents reveal data collection problems associated with resident behaviors. Data is missing on some days, shifts, and hours, or is not recorded up to the current time or interval. Improper or incomplete data collection can negatively impact initial assessments and progress re-assessments, which can influence service delivery. It also does not appear that residents' behavior programs are updated frequently enough to address changes in residents' behaviors throughout the course of the year. As we discuss below, this is especially notable with regard to residents who are continually subjected to invasive restraints.

The overriding and primary problem at BSDC, however, is not so much with the paper programs as it is with the inadequate implementation of the paper. Consistent and correct implementation of adequate and appropriate behavior programs is required if progress is to be made on the behavior programs. Yet, staff at BSDC fail to properly implement the written behavior programs for the residents. This is a pervasive problem that implicates staff across all shifts and settings. Poor implementation of programming places BSDC residents with behavior problems at risk of continued harm, continued exposure to restrictive intervention procedures, and continued institutionalization.

There are many reasons for implementation deficiencies. Staff vacancies are a contributing factor. Our psychology consultant characterized the large number of staff vacancies at BSDC as a "huge gap in staff." The loss of experienced staff and the high rate of staff turnover are also taking their toll. The behavior programs at BSDC involve multiple distinct steps or procedures. New staff, temporary staff, "on-call" staff, or staff pulled from other units are often unfamiliar with the particulars of the lengthy and detailed individual behavior programs. This leads to faulty implementation. Even with regular staff though, it is too often the case that they are not familiar enough with the programs to implement them correctly. Our

psychology consultant concluded that “[l]ack of experienced trained staff to work with the difficult complex cases that I reviewed can have a devastating effect on the quality of behavior program implementation.” He added that “the presence of adequate staff was highly correlated with calmness of the [BSDC living] unit.”

When confronted with a resident behavior, generally accepted practice and BSDC policy require staff to systematically work through a progression of less restrictive techniques before applying more invasive measures. However, instead of methodically and properly implementing the written program, hurried staff in a behavioral crisis too often and too quickly resort to reactive procedures. The facility staff often do not move systematically through the BSDC continuum of interventions from least restrictive intervention to more restrictive intervention as required by State policy. Fundamental program elements, such as modification of antecedents or attempts at prevention, including gently talking to the individuals or redirecting them from the environment, are not employed properly or as often as needed. Instead, facility records reveal a rather consistent reaction to behavioral problems, where staff quickly move from behavior response blocking to physical restraints to mechanical restraints.

As a result of the failure of behavioral training at BSDC, the residents with problem behaviors, as well as those in their proximity, have remained at risk of harm due to the consequences of the unchecked problem behaviors. The resident-to-resident aggression we referenced above is one example of this. Because the problem behaviors continue, these residents are then subjected to other means of control, such as the use of highly restrictive interventions, including emergency mechanical restraints.

2. Restraints

The Supreme Court has recognized that the right to be free from unreasonable bodily restraint is the “core of the liberty protected by the Due Process Clause from arbitrary governmental action.” Youngberg v. Romeo, 457 U.S. at 316, 322 (citing Greenholtz v. Inmates of Neb. Penal and Corr. Complex, 442 U.S. 1, 18).⁷ See also 42 C.F.R. § 483.13(a)(resident “has the right to be free from any physical or chemical restraints . . . not required to treat the resident’s medical symptoms.”). Consistent with generally accepted professional practices, restraints are to be used only when justified and only when there is evidence that less restrictive procedures have been proven ineffective or are unsafe.

⁷ The Supreme Court has held that this interest is fully applicable to individuals with developmental disabilities who are confined to state institutions. See Youngberg, 457 U.S. at 316. The Court noted that the state is under a duty to provide an institutionalized person with a developmental disability with reasonable training “to ensure his safety and to facilitate his ability to function free from bodily restraints. It may well be unreasonable not to provide training when training could significantly reduce the need for restraints or the likelihood of violence.” Id. at 324.

The State subjects BSDC residents to undue restraints. From June 1, 2006 to August 31, 2007, the State reports that 79 BSDC residents, approximately 25 percent of the population, were restrained. Restraints at BSDC can range from a physical restraint where a staff member physically holds a resident's head, limb(s), and/or body, all the way to a mechanical restraint (the most invasive form of restraint) where staff use cloth and leather straps to tie to a bed a resident's four limbs and sometimes his or her chest. Commonly used behavior management procedures at BSDC are very restrictive and pose significant risk of injury to BSDC residents. These highly restrictive interventions include: mechanical restraint devices that involve 2-point or 3-point restraints (arms and/or legs), 4-point restraints (arms and legs), or 5-point restraints (arms and legs and the upper or lower body). These interventions may be used either on a programmatic or on an emergency basis. The facility staff also engage in the highly restrictive practice of physical holds that allow up to three staff members to lift and carry a resident against his or her will.

Our psychology consultant concluded that restraint usage at BSDC is high. Indeed, he labeled mechanical restraint usage at BSDC as "the highest in frequency and duration that I have seen in my experience." Our safety consultant characterized as "alarming and disconcerting" the risks associated with the duration and frequency with which several residents are placed in restraints. The specific restraint numbers at BSDC are rather staggering:

- During the period from June 1, 2006 to August 31, 2007, the State reports that there were 896 total restraint episodes; this represents an average of about 60 restraint episodes every month at BSDC.
- During this period, resident HK was restrained 104 times, resident OK was restrained 70 times, resident PL was restrained 49 times, resident CF was restrained 48 times, and resident UL was restrained 43 times. There were 17 other residents who were restrained a dozen or more times during this period.
- The use of the most invasive form of restraint – mechanical restraints – is quite prevalent at BSDC. During the 15-month period referenced above, BSDC staff placed residents in emergency or programmatic mechanical restraints (i.e., those utilized pursuant to a behavior program) for a total of 41,168 minutes, or over 686 hours. The use of programmatic invasive restraints alone averaged about 44 hours per month.
- Many of the individual restraint episodes have been very lengthy, with some lasting several hours at a time. During this period, 24 residents were subjected to at least one invasive mechanical restraint episode of two consecutive hours or more.
- Resident RM was placed in mechanical restraints for two hours or more a total of 26 times during this period. Many other residents suffered through mechanical restraints for two hours or more: resident PL, 22 times; resident OK, 21 times; resident HK, 15 times; resident EH, 14 times; and residents CF and SN, 9 times each.

- During this period, there were 65 separate instances where staff subjected residents to mechanical restraints of three hours or more; of these, 22 separate instances lasted five or more consecutive hours; of these, seven lasted seven or more consecutive hours.
- In late October 2006, in response to what was characterized as “edgy” behavior where a resident was hitting, kicking, scratching, and biting, staff placed the resident in four-point restraints for a total of 23 hours and 41 minutes straight (with one ten-minute break just before the 12-hour mark). Staff noted that this resident may have been craving additional attention, which apparently was denied him other than in the context of a restraint application.
- During this period, resident RM was placed in invasive mechanical restraints for a total of 8,618 minutes, or over 143 hours. Resident OK was placed in such restraints for about 85 hours; resident PL for over 75 hours; and resident HK for over 65 hours.
- Staff subjected seven BSDC residents to emergency mechanical restraints during this time for over 1,000 total minutes. All but three of the individual restraint applications lasted for an hour or more; resident TO was placed in emergency mechanical restraints for five hours on one occasion and over three hours on another.
- During this period, mechanical restraint usage prompted 49 separate facility critical incident reviews involving over a dozen residents.

Our safety consultant concluded that injuries sustained during restraints are “increasing rapidly at BSDC and are indicative of a systemic problem at the facility.” She concluded that BSDC’s inability to protect residents from harm prior to and during the restraint application is a significant departure from minimally accepted standards of practice.

While the facility has a restraint review committee that meets regularly to review the use of restraints on certain individuals, it does not appear to be having much impact on the use of restraints at the facility, especially with regard to residents with difficult behavior problems. These timely meetings are characterized by a general sensitivity to the need to reduce restraints. However, this does not necessarily mean that insightful professional input is always presented at these meetings or that action steps are developed that will lead to more effective behavioral interventions for residents.

Separately, as we discuss below, several converging factors, in addition to behavioral service deficiencies, produce an environment where resident behaviors and restraints are likely to occur; these include: an overly restrictive segregated living environment characterized by crowded conditions with almost constant close exposure to other residents prone to behaviors; lack of adequate habilitation and meaningful community activities during the day; and issues related to the provision of psychiatric care for those with mental illness.

3. Overly Restrictive Environment

The overly restrictive physical environment of the BSDC institution limits behavioral treatment options. Crowding in some residential units causes tension and increases the likelihood that behavior problems will arise, especially where two or more aggressive residents are in close physical proximity to one another for virtually the entire day and night. Our psychology consultant informed us that none of the aggressive residents he talked to during the week said that they had a friend on their unit. He concluded that "confining people who are predisposed to aggression and who do not like one another in the close quarters of the living units of BSDC is a program for trouble."

Moreover, the facility has not done enough to integrate residents into community settings, as discussed below. One consequence is that residents have limited opportunities to associate with people who may be role models for socially appropriate behavior. This is most easily accomplished through community placement and/or integrated and meaningful activities during the day, including supported employment and positive behavioral support activities.

Ironically, the facility's overcrowded and confining environment and its failure to adequately address residents' problem behaviors makes it more difficult for many of these residents to transition to more integrated community settings or to participate in more integrated day activities. The treatment plans of some residents reveal that interdisciplinary teams at BSDC at times appear reluctant to recommend a resident for placement or services in a more integrated community setting if the resident has significant problem behaviors. This is tragic because many residents were transferred to BSDC for the sole purpose of ameliorating their problem behaviors.

4. Habilitation, Vocational Activities, and Meaningful and Integrated Day Activities

Persons with developmental disabilities are to receive adequate habilitation training and related vocational and day program services and supports so that they may acquire new skills, grow and develop, and enhance their independence. Federal law requires that:

Each client must receive a continuous active treatment program, which includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services . . . that is directed toward - [t]he acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible; and . . . [t]he prevention or deceleration of regression or loss of current optimal functional status.

42 C.F.R. § 483.440(a). Indeed, both the BSDC habilitation and behavior program policies stress the need to help residents attain and increase skills in direct response to each individual's needs and personal outcomes. However, BSDC fails to provide its residents with such adequate habilitation training and related services and supports.

Our psychology consultant noted that while "BSDC professes to be an active treatment facility, . . . some staff appear not to buy into that mission." During our visit, we discovered a low level of staff interaction with the residents throughout the day. Too often, residents were not engaged, and the staff did not attempt to engage them in meaningful habilitation activities. We found several situations where nothing was happening with residents even though staff were present. This lack of meaningful training and activity not only denies residents an opportunity to learn and grow, but it can set the stage for the residents to engage in harmful behaviors.

Even at pleasant on-campus facilities, such as the Carstens Center, with a gym, a pool, a social center, and a game area, participation is rather limited. BSDC logs reveal that, on many days, only a handful of residents use the Carstens Center; "no-shows" for scheduled activities are common. Facility records reveal that, in June 2007, almost 20 percent of the residents were labeled as "no shows" for aquatic therapy. Quality assurance staff repeatedly labeled this a "big concern." Throughout the week of our visit, certain BSDC staff revealed that they hardly ever take residents to the pool. It was not clear to staff why this was the case. Moreover, internal quality assurance documents reveal that many staff do not interact with the residents when in places of habilitation and training, such as the social center or the gym. Instead, staff sometimes "just sit and let the individuals run around hitting and throwing balls at each other." At times, there are not enough age-appropriate materials for training purposes.

Persons with developmental disabilities are to receive habilitation services in integrated settings wherever possible. See the Americans with Disabilities Act, 42 U.S.C. § 12132, and the requirement that services be provided in the "most integrated setting." However, the State has failed to provide adequate, meaningful, integrated activities in the community for BSDC residents. No resident attends school off campus and no resident receives programming off campus. Only one resident works significant hours in a competitive, supported employment setting in the community. Instead of emphasizing community involvement, BSDC has concentrated on providing work and programming to dozens of residents in various sheltered workshop settings on the segregated campus. Moreover, most of the work and programs on campus involve rote and repetitive tasks.

While BSDC recently appears to have been making a positive effort to increase occasional community outings for BSDC residents, such as to the grocery store or to the park, the number of residents who participate is limited, as are the number of days and hours per day they can go to the community at any given time. BSDC records reveal that, instead of going to the community each day for several hours or most of the day, residents are typically able to go to the community only a handful of times each month for just a couple of hours each time. By contrast, the ITS, which emphasizes the importance of individuals staying connected to the community, is able to take the individuals enrolled in its program off campus much more regularly than the typical BSDC resident is able to go off campus. We learned, for example, that each ITS resident goes off campus almost every day for several hours a day.

Thus, the State appears to recognize the importance of community integration, but it has not done enough to maximize residents' day-to-day integration with the community at large beyond the BSDC campus. This is somewhat remarkable given that staff reported to us that residents generally enjoy community trips; that typically resident behaviors and their overall welfare and demeanor improve markedly when engaged in meaningful, integrated activities; and that community involvement enhances learning. Staff also informed us that restraint usage goes down markedly once residents are in the community. In any event, staffing, transportation, and the availability of other resources appear to be limiting factors. For example, even if every off-campus BSDC vehicle was utilized at one time, about half of the residents could not be accommodated on community trips. Moreover, BSDC has vehicle capacity only for fewer than two dozen residents who use wheelchairs.

5. Psychiatric Disorders and Treatment

As part of the interdisciplinary approach to addressing residents' behavior problems, generally accepted practice requires that State-operated facilities like BSDC provide adequate psychiatric services for its residents with mental illness. Traditionally, persons with developmental disabilities, who also have a dual diagnosis of mental illness, have been under-diagnosed and over-medicated, especially if they lived in an institutional setting like BSDC. In the past, the inherent difficulty and complexity of identifying and treating the often subtle signs and symptoms of this population led to mistreatment or missed treatment; sometimes the need to gain control of problem behaviors led to clinically imposed chemical restraint. The ongoing dangers associated with certain behavioral and psychiatric treatments for this population demand continued vigilance to protect against inertia and/or abuses against vulnerable persons with developmental disabilities and mental illness.

As of September 13, 2007, the State reported that 167 BSDC residents had an Axis I disorder diagnosis.⁸ The vast majority of these individuals have mental illness. Several dozen residents have more than one mental health diagnosis. The State reports that 152 residents receive at least one psychotropic medication. Over 86 percent of all BSDC residents with a behavior program also receive psychotropic medication.

In spite of our overriding concerns, there are positive elements with regard to providing psychiatric care to BSDC residents: there is often frequent contact with residents by professionals responsible for providing mental health care; overall there is a thoughtful, multi-disciplinary team approach to delivering mental health care; in conducting diagnostic assessments there is an effort to use objective information to guide clinical decision-making; and

⁸ Pursuant to the American Psychiatric Association's diagnostic criteria manual, Axis I disorders are clinical disorders and/or other conditions that may be a focus of clinical attention. Typically, these clinical disorders include mental illness. Mental retardation and personality disorders are classified as falling under Axis II. The aggregate figure above does not include the 11 persons at Bridges, all of whom have issues with regard to mental health treatment.

the facility uses accepted monitoring tools to screen for psychotropic side effects and movement disorders. Nonetheless, as we discuss below, too often, resident outcomes suffer because of outstanding deficiencies in this area.

The overriding deficiency is that there is currently not enough psychiatry time to provide adequate psychiatric care to meet the needs of BSDC residents with mental illness. This places BSDC residents at risk of harm. In the past, the BSDC residents were served by a psychiatrist with nearly 20 years experience treating persons with developmental disabilities who was at the facility on almost a full-time basis. Now, the consulting psychiatrist to BSDC visits residents at the facility on a limited and part-time basis, about two days per month. Individual evaluation appointments typically appear to be scheduled in a range from about five minutes to 15 minutes for each resident. (The team meetings conducted in the presence of our consultant psychiatrist lasted slightly longer.) Our psychology consultant concludes that this "simply is not enough examination time for a thorough DSM assessment or even follow-up examination. Much more time evaluating each client is needed." Under his current contract, at most, the consulting psychiatrist can spend an average of about 69 minutes annually per resident with a current Axis I diagnosis. Our psychiatry consultant concludes that this "would be considered insufficient for even the most stable patient in complete clinical remission."

The lack of sufficient psychiatry hours produces infrequent evaluation and assessment of residents and less frequent follow-up than is needed. It also makes it more difficult to change treatments that would be likely to require additional psychiatry time in the future than is available under the current contract. We understand that the consulting psychiatrist is often not able to see every resident who has been referred to him that day for consultation. As a result of all this, the BSDC primary care doctors, a physician assistant, and a registered nurse are now responsible for providing a sizable volume of psychiatric follow-up care. As our psychiatry consultant concludes, "[o]ther clinicians can provide some mental health care and assessment for short periods of time, but cannot substitute for psychiatric expertise for long term treatment."

In looking at outcomes for residents, our psychology consultant, who is also a nationally recognized expert in psychopharmacology, concludes that many residents at BSDC are "grossly over-medicated." He concludes that psychotropic medication usage at BSDC is high and that the percentage of residents subjected to psychotropic polypharmacy is high. With regard to individual doses, he concludes that "[d]oses used are higher than any I have seen in many other facilities across the country, as well as the one I worked at for ten years in the 1970s." He added that the effective doses of several medications are half those used at BSDC. He also found that the decision-making process for titrating drugs up or down after review of their effects on behavior is often not clear in the records; the psychiatric consult reports in the medical records are very brief, containing minimal information; and the coordination of psychological and psychiatric evaluations is not clearly evident in the individual charts.

Our consultant psychiatrist listed a host of concerns as well with regard to the delivery of psychiatric care to dually diagnosed BSDC residents, including:

- Moderate-to-high doses of typical or “first-generation” anti-psychotic medications are too often used without sufficient clinical justification. These residents face the potential harm of excessive exposure to the long-term risks of these medications, including tardive dyskinesia and Parkinsonism.
- In too many cases at BSDC, there is general therapeutic inertia where teams are often content to maintain the status quo, sometimes even in the face of the possibility of medication side effects or other negative consequences of psychotropics. This includes failure to reduce or discontinue medications in light of clinically significant intervals with no symptoms, and failure to change treatment in spite of new and significant symptoms. Given outside opposition to some medication changes, the facility is not doing enough to educate and address the concerns of parents and guardians when medication changes are needed to provide the resident with acceptable psychiatric care.
- There is some diagnostic-therapeutic disconnect, where the resident’s diagnosis does not obviously explain the psychotropic regimen in place. When this happens, typically there is insufficient explanation or justification in the individual records for the clinical decision-making. In these cases, the potential to harm the resident is two-fold – the person may be treated with inappropriate and/or unnecessary medications and, at the same time, will not be receiving proper treatment for his or her underlying mental illness.
- For certain BSDC residents with anxiety and/or insomnia, there is chronic use of low-to-moderately high doses of benzodiazepines, which does not reflect good practice in persons with intellectual disabilities because this class of medications diminishes cognition. Too often, benzodiazepine are used at excessive doses and/or for longer periods of time than appeared justified by the individual’s psychiatric diagnosis. Such use places these individuals at risk for psychological dependence, tolerance, excessive side effects, and a loss of inhibition with regard to certain behaviors.
- Some intra-class polypharmacy is used without sufficient clinical justification. Exposing persons to intra-class psychotropic polypharmacy is generally considered to be poor practice. Risks include unnecessary and additional side effects and potential drug-to-drug interactions that would not be present if only one agent was used.
- BSDC needs better and close coordination among behavioral, psychiatric, and neurologic treatments, as several mood stabilizing drugs used to treat psychiatric disorders are also effective in treating seizure disorders. Moreover, most current anticonvulsant medications are psychoactive and can have behavioral side effects. Without close coordination, the potential for harm associated with drug-to-drug interactions may go unrecognized. BSDC sometimes draws an artificial distinction between whether a medication is being used for seizure disorders, psychiatric disorders, or behavioral management. In some cases, an anticonvulsant used for seizure disorders is not discussed at all in psychiatric notes even though it is clearly psychotropic.

- The long-term use of anticholinergic medications for the treatment of side effects should be avoided. However, too often at BSDC, residents receive these medications for long periods of time without discussion of either the ongoing need or attempts to reduce the dosage. This exposes residents to the needless exposure to the side effects of these medications.

BSDC utilizes the DISCUS⁹ for monitoring side effects. The DISCUS is commonly used among mental health practitioners for this purpose. However, our psychology consultant concludes that certain questionable DISCUS scores at BSDC revealed that the staff is not using the DISCUS properly, calling into question whether or not the staff are adequately trained. In any event, more information from side effects and movement disorder monitoring should be included in psychiatric progress notes to document that the clinician is aware of and utilizing this information in decision-making. If risks are not identified, harm to the resident could result.

C. HEALTH CARE AND RELATED SERVICES

The Supreme Court has determined that institutionalized persons with developmental disabilities are entitled to adequate medical care. Youngberg v. Romeo, 457 U.S. at 324. The Court labeled this as one of the “essentials of care that the State must provide.” Id. The Court specifically referenced persons with degrees or training in medicine, nursing, and physical therapy as some of the health care professionals covered by its decision. Id. at 323 n.30.

1. Medical and Nursing Care

In a number of respects, BSDC too often fails to provide residents with adequate health care. The facility fails to develop and implement individualized plans for preventive care consistent with generally accepted practice. Overall, the health care at BSDC is more reactive than proactive, where the residents, especially those with complex and high-risk conditions, often do not receive adequate preventive health care; the facility does not do enough to identify, assess, treat, and monitor these high-risk residents.

In general, the facility does not provide good interdisciplinary care. There is often inadequate collaboration and coordination between and among the various health care disciplines, especially with regard to complicated resident cases. Separate disciplines often fail to work together well, which leads to fragmented silos of health care activity that occur on largely parallel tracks. The multiplicity of charts for the same individual hampers communication among professionals and staff and impedes coordination of efforts. The charts often do not reflect adequately the health care decision-making process. The charts also do not reveal clearly what is happening with residents. Current and future plans for care are difficult to

⁹ DISCUS is the acronym, widely recognized among mental health professionals, for the “Dyskinesia Identification System: Condensed User Scale.”

discern from the charts, placing residents at risk of harm because of poor communication and lack of coordination about their care and treatment.

All this has great implications for residents at risk for, among other things, bowel impactions and obstructions, pneumonia and aspiration pneumonia, skin breakdown, seizures, and fractures due to osteoporosis.

Bowel impactions and bowel obstructions are typically preventable conditions, that can lead to discomfort, perforations, and even death, if left unaddressed. Generally accepted practice dictates that care givers must be vigilant and take extra steps to prevent impactions or obstructions, especially among persons with developmental disabilities who are non-ambulatory and face other contributing risk factors. This is a significant concern at BSDC, as the facility identified over two dozen residents who are at "high risk" for impaction or bowel obstruction. This list apparently does not include all those who are truly at risk though. For example, a handful of residents visited or were admitted to a hospital for abdominal issues in the year before our visit, but were not even included on the facility list of those at "high risk." This includes resident VQ (hospitalized in June 2006 for fecal retention with impaction) and resident UP (hospitalized in March 2007 for abdominal pain). It is troubling that from June 1, 2006 to August 31, 2007, the facility listed over a dozen instances where residents had to be transferred to off-campus acute care facilities or emergency rooms to get treatment for impaction, obstruction, or abdominal pain, abdominal distension, or other related conditions. Resident AR (age 37) died on September 12, 2007, after a year of serious abdominal issues, including hospital visits or admissions for abdominal pain in December 2006, intense abdominal pain and a retracted ileostomy in March 2007, abdominal pain and distention in April 2007, and an ileus treatment in May 2007.

Aspiration pneumonia is typically a preventable condition that results from the accumulation of foreign materials (usually food, liquid, or vomit) in the lungs. BSDC lists only ten residents as at "high risk" of aspiration or choking, yet several residents were hospitalized for aspiration- or choking-related events who do not appear on the facility's high risk list, including resident BS (hospitalized in September 2006 for possible aspiration pneumonia), resident CT (hospitalized that same month for an airway obstruction), resident DU (hospitalized in December 2006 and January 2007 for vomiting blood and respiratory distress), resident EV (hospitalized in March 2007 for aspiration pneumonia), and resident FW (taken to the emergency room in August 2007 for upper air congestion). This calls into question whether or not BSDC is adequately identifying and treating all those residents at risk of aspirating or choking. Resident ZA died in January 2007, with aspiration pneumonia listed as her cause of death. Several other residents are listed as having died or been hospitalized, at least in part, due to pneumonia, although it is not clear if these pneumonia events were caused by aspiration.

A decubitus ulcer or skin breakdown is another entirely preventable condition given appropriate proactive care. As with other conditions, BSDC is failing to identify all those residents truly at risk and this hampers or eliminates the possibility of providing proper

preventative services and supports. For example, in 2007, through October 16, the facility reported that nine different residents suffered a skin breakdown. However, BSDC only listed a total of seven residents as at "high risk" for skin breakdown. Moreover, it is troubling that seven of the nine residents who actually suffered from skin breakdown did not appear on the facility's high risk list. This speaks, in part, to poor communication and coordination between and among various health care disciplines. Although one health care professional might identify a resident as being at high risk for skin breakdown, this information may be buried in a progress note or a consult form, and often does not reach other health care staff critical to the resident's care. Resident AD suffered numerous skin breakdowns in the year before our visit and there were notations about this in his chart, but he was not on the facility's list of residents at risk of skin breakdown or on the list of those who had actually suffered skin breakdown. On October 12, 2007, occupational therapy staff evaluated AD and found no problems. Several hours later though, a member of the nursing staff noticed that AD, in fact, was suffering from a stage-two pressure ulcer. The nurse requested that the therapists return promptly to conduct a re-evaluation, but this was not done. Instead, three days after the nurse noted the ulcer and made the request, a member of the therapy staff wrote the following note in the file: "The seating system was evaluated by OT on 10/12/07. The seating system continues to be adequate for [AD] with no pressure areas noted." We found other residents who were not included on the risk list even though they had therapist notations that they were at high risk. These examples call into question whether or not BSDC is identifying and properly treating all those who are truly at risk.

At the time of our visit, BSDC listed 193 residents as having a seizure diagnosis of some sort. About 80 percent of these individuals are listed as having active seizures. There are 30 residents who had two dozen or more seizure episodes during the period from June 1, 2006 to August 31, 2007. A number of residents appear to have complex cases characterized by very frequent, poorly-controlled seizures. For example, during this period, resident FI had 210 seizures, resident GX had 100 seizures, resident XY had 128 seizures, resident RF had 106 seizures, and resident HY had 170 seizures. During this period, several residents had to be taken to area hospitals to treat seizures or to address a change in neurological status. Similar to the arrangement with the consultant psychiatrist, the consultant neurologist visits BSDC to see residents about two days per month. This is not enough time to adequately meet the needs of the dozens of residents with often complex seizure disorders at BSDC.

In the year before our visit, 15 BSDC residents died. While two residents had lived into their nineties, three residents died in their thirties – one from aspiration pneumonia, which is typically a preventable condition. Indeed, pneumonia was listed as the cause of death for other BSDC residents. It was troubling to learn that the cause of death for at least two residents was colon cancer; apparently, in these cases, the cancer had progressed and then spread to other parts of the body. These cancer victims were relatively young, aged 44 and 50. It is unclear whether or not the facility took adequate preventive steps to detect the cancer at an early enough stage.

In a facility like BSDC, it is very important to identify whether or not each death was preventable. Given that persons with developmental disabilities may not be able to communicate

signs and symptoms well or at all, it may be more difficult for care givers to determine if the course of treatment selected is or was actually working. Effective and in-depth mortality reviews can enhance this incomplete knowledge about the adequacy of care by identifying weaknesses and deficiencies in health care delivery. This can then prompt the development and implementation of remedial measure that will eliminate preventable illness and death for other similarly situated residents. Unfortunately, this is not done well presently at BSDC. The mortality review process at BSDC is inadequate. Rather than conducting a critical and meaningful review of the adequacy of the course of care in the weeks and months leading up to each death at the facility, the mortality review process at BSDC appears to be designed primarily to excuse from further scrutiny the BSDC health care provider(s) involved in the care of the deceased resident. Indeed, our health care consultant looked at two dozen death reviews spanning nearly two years prior to our visit; none contained recommendations about what steps could or should be developed and implemented to eradicate preventable causes in the future.

Infection control at BSDC is often deficient. Although the facility reports the number and types of infections, it fails to follow its own procedures, which also require reporting on whether an infection is caused by a caregiver. Such infections, which are always preventable, may occur, for example, where a caregiver fails to wash his or her hands or use the proper sterile procedures. Unfortunately, hand-cleansing facilities are not consistently accessible on all the BSDC units. This is of great concern because proper hand cleansing is critical in the prevention of infectious illnesses and is particularly important in a facility like BSDC, which houses a number of medically fragile residents.

From mid-2006 to mid-2007, BSDC averaged about 125 medication errors per quarter. While there were 158 medication errors in the fourth quarter of 2006, the number had declined to 108 errors in the third quarter of 2007. Although the facility reports no deaths or permanent harm associated with any medication error, nonetheless, some of the medication errors are serious and place residents at risk of harm, sometimes necessitating increased monitoring, and in a handful of cases, observation in a hospital setting. While the facility reports a very low error rate when measured as a percentage of total doses administered, nonetheless, on average, there is more than one medication error every single day at BSDC.

While the health care and other staff are dedicated, it is clear that staffing shortages have compromised care and helped contribute to service delivery problems. There are not enough registered and other nurses at BSDC to meet the needs of the residents. At times, there is inconsistent nursing coverage. Moreover, on-call staff and pulled staff at times contribute to medication errors. Staffing concerns also unnecessarily increase the workload of the nursing and other health care staff.

The BSDC professional health care staff has become unnecessarily isolated from professional organizations or societies related to providing health care and other services for persons with developmental disabilities. Membership and active participation in such entities may provide professional staff with access to up-to-date information and resources in this

specialized area and help them provide more effective health care to BSDC residents. The failures in this area may be a consequence of the overworked BSDC staff not having time to tend to professional development.

2. Nutritional and Physical Management

Nutritional and physical management services are a significant aspect of adequate health care services for persons with developmental disabilities. These supports can minimize risks associated with swallowing difficulties, digestion problems, misalignment, and skin breakdown, so as to avoid preventable hospitalizations associated with aspiration pneumonia, gastrointestinal problems, and decubitus ulcers. Unfortunately, residents do not receive adequate nutritional or physical supports at BSDC. In this area especially, vulnerable at-risk residents need proactive care to get ahead of problems that can lead to illness and hospitalization. Current care at BSDC, however, is too reactionary; evaluations are conducted only when a problem arises.

Although BSDC has a dysphagia committee, the committee's scope is too limited and narrow; it does not proactively and comprehensively address the wide-ranging needs of the very vulnerable population. In fact, the committee does little more than merely address global issues, such as the need for thickening agents for liquids for residents who have difficulty swallowing. The committee fails to address the individualized needs and concerns of the highest risk residents at BSDC.

The facility as a whole needs to better identify and address the needs of those residents who are most at risk. Simply having a limited dysphagia team is not enough. More needs to be done to minimize residents' risk and maximize their skill acquisition. Overall, there needs to be more of a proactive, cooperative, collaborative, systemic team approach to addressing nutritional and physical support issues. Otherwise, the risk of aspiration pneumonia and other gastrointestinal problems and hospitalizations will remain unnecessarily high for certain BSDC residents. Indeed, the lack of such adequate services and supports can be fatal, as it was for IZ, a resident who was fed by g-tube. Several months prior to her death, the dysphagia team re-evaluated IZ because she had been having several episodes of increased coughing associated with oral feedings. Instead of discontinuing all oral intake, the facility continued to provide IZ with both g-tube and oral feedings. IZ died shortly thereafter, with the cause of death listed as pneumonia bacteremia, a lung infection that turns into a blood infection. In reviewing the course of IZ's care, our consultant determined that there was a significant likelihood that aspiration contributed to IZ's death and that stopping oral intake may have removed a contributing factor to her death. This is potentially a larger issue, as at the time of our visit, there were about 71 BSDC residents who use a feeding tube.

It is positive that the facility has implemented family-style dining for residents. Nonetheless, the facility needs to do more to ensure that individual diets are maintained in the context of family-style meals, especially for those on low-sodium and/or low-calorie diets.

Almost every resident has or is supposed to have an evaluation by physical and occupational therapy staff. Most residents need services and supports from one or both disciplines, with some needing more intensive care. For example, there are 81 residents with a 24-hour re-positioning program and there are 18 residents listed as at "high risk" of developing contractures. Unfortunately, physical and occupational therapy services at BSDC are not adequate. As a result, residents face an increased risk of contractures and deformity, resulting in a loss of independence and functional skills. The implemented plans are rote, not functional, and rather meaningless. To be meaningful, therapy needs to be generalized to all settings, and not just occur in a vacuum at the therapy clinic. At BSDC, however, the therapy provided is too often not integrated back to the residents' lives. For example, merely lifting a leg weight at the clinic may not easily translate to a resident's increased function in a real-life setting outside the clinic. Moreover, too often, goals for residents are set at levels the person has already achieved – and written plans are essentially identical year after year. In short, it appears that the mindset at BSDC is that maintenance is acceptable. None of this helps the residents learn or acquire skills so that they can gain functional independence in their current setting and later, in the community. To the contrary, BSDC's current system allows for regression, and may even play a role in helping to prevent certain residents from being placed back in the community.

It is critical that facilities like BSDC design and implement plans that meet the individual needs of each resident, instructing staff how to perform activities like positioning the resident in a wheelchair or applying braces or orthotics. Nonetheless, BSDC fails to implement any such plans. Although instructions for the use of assistive devices like wheelchairs and braces generally are located on the units, these are broad blanket directions, and do not take into account residents' particular needs. Further, the facility fails to monitor residents' progress in a timely manner, and instead, simply conducts re-evaluations in the normal course, and not always when changed circumstances dictate.

On the positive side, while at the facility, we observed an excellent hands-on training session given by two of the therapists. We are unclear, however, as to whether this is representative of all the therapy training offered, and whether the trainers go on-site to check on the continued competence of the staff.

Assistive technology is also a critical component of providing adequate communication and other supports to persons with developmental disabilities. There are about 117 residents with some form of speech or communication program, 37 residents with a communication device, and 17 residents with adaptive equipment for hearing assistance (6 residents elect not to use the devices). Unfortunately, BSDC's approach to assistive technology is fragmented and not team-oriented. BSDC lacks sufficient coordination and collaboration between and among the various disciplines, especially with regard to the need for proper communication devices on wheelchairs. For example, communication goals and expected outcomes for communication devices should be part of any assessment for assistive technology, such as seating or other mobility devices. The therapists involved in the assessment and selection of assistive technology must work closely together to meet each resident's individualized needs. At BSDC, however,

individual therapists conduct unilateral assessments for each aspect of the assistive technology, with no documentary evidence in the charts or elsewhere that they collaborate with one another. As a result, particular pieces of assistive equipment too often do not meet the comprehensive needs of the resident for whom they are intended.

In addition, the facility fails to provide sufficient assistive communication systems to all residents who would benefit from such supports. Although it is positive that the high-tech assistive communication devices we observed at the facility were all operational, the facility does not provide sufficient low-tech systems, which may benefit many other residents who require assistive technology supports for independent communication.

Finally, as is true in other areas, staffing concerns exist within the disciplines that provide health care and nutritional and physical supports to BSDC residents. Currently, BSDC does not have enough clinicians to provide adequate physical therapy, occupational therapy, or speech therapy to meet the needs of residents who require these services. For example, despite the fact that communication is a basic need of all residents, the facility has only two speech therapists; a third speech therapy position was frozen at the time of our visit. Two speech therapists are not enough to meet the needs of BSDC residents.

D. SERVING PERSONS IN THE MOST INTEGRATED SETTING APPROPRIATE TO THEIR INDIVIDUAL NEEDS

In addition to providing residents with adequate safety, training and behavioral services, freedom from undue restraints, psychiatric care, health care, and other related supports and services, federal law requires that the State actively pursue the timely discharge of institutionalized residents to the most integrated, appropriate setting that is consistent with the residents' needs.

In construing the anti-discrimination provision contained within the public services portion (Title II) of the Americans with Disabilities Act ("ADA"), the Supreme Court held that "[u]njustified [institutional] isolation . . . is properly regarded as discrimination based on disability." *Olmstead v. L.C.*, 527 U.S. 581, 597, 600 (1999). Specifically, the Court established that states are required to provide community-based services and supports for persons with developmental disabilities when the state's treatment professionals have determined that community placement is appropriate, provided that the transfer is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities. *Id.* at 602, 607.

The regulations promulgated pursuant to the ADA provide: "A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d) (the integration regulation). The preamble to the regulations defines "the most integrated setting" to mean a

setting "that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible." 28 C.F.R. pt. 35, App. A at 450.

Further, with the New Freedom Initiative, President George W. Bush announced that it was a high priority for his Administration to tear down barriers to equality and to expand opportunities available to Americans living with disabilities. As one step in implementing the New Freedom Initiative, on June 18, 2001, the President signed Executive Order No. 13217, entitled "Community-Based Alternatives for Individuals with Disabilities." Specifically, the President emphasized that unjustified isolation or segregation of qualified individuals with disabilities in institutions is a form of prohibited discrimination, that the United States is committed to community-based alternatives for individuals with disabilities, and that the United States seeks to ensure that America's community-based programs effectively foster independence and participation in the community for Americans with disabilities. Exec. Order No. 13217, §§ 1(a)-(c), 66 Fed. Reg. 33155 (June 18, 2001). The President directed the Attorney General to "fully enforce" Title II of the ADA, especially for the victims of unjustified institutionalization. Id. at § 2(c).

Where community transition does occur, the state is responsible for providing adequate follow-along services. See Armstead v. Coler, 914 F.2d 1464, 1467 (11th Cir. 1990); Thomas S. v. Brooks, 902 F.2d 250, 254-55 (4th Cir. 1990); Halderman v. Pennhurst State Sch. and Hosp., 834 F. Supp. 757, 766 (E.D. Pa. 1993). These follow-along services should include face-to-face visits with the transitioned resident; interviews with staff, family, and guardians; and careful review of the transitioned resident's records. Accordingly, the State should utilize measurable criteria by which to ensure that transitions from BSDC are implemented as planned and that individuals transitioned are safe and healthy in their new environments.

As set forth below, the State is failing to comply with the ADA with regard to placing persons now living in BSDC in the most integrated setting appropriate to their needs.

1. Community Placements from BSDC

In general, there appears to be a sensitivity within the State to the importance of serving persons with developmental disabilities in the most integrated community setting according to their individualized needs. We understand that the State's position is that almost all BSDC residents could be served in the community with adequate and appropriate protections, supports, and services. Indeed, the Nebraska Health and Human Services Department system manual emphasizes that the State strives to offer a community system of supports and services intended to allow individuals with developmental disabilities "to maximize their independence as they live, work, recreate, and participate in their communities." It is notable that the State's policy is that all placements at the BSDC institution are considered to be temporary. A separate State policy provides that all individuals residing at BSDC are eligible for referral for placement from BSDC and for transition to a community provider. Indeed, throughout our visit, BSDC staff acknowledged that persons with developmental disabilities generally can benefit from

community placement. In spite of this, the State has not yet developed a written “Olmstead Plan,” which most states have developed to foster placement of persons with developmental disabilities to more integrated community settings.

As of August 31, 2007, the State reported that 296 current BSDC residents – over 90 percent of the overall census – had an interdisciplinary team recommendation for community placement. The team recommendations are contained in individual BSDC Personal Plans. Invariably, the BSDC team determines that a referral for placement “should be continued.” It is positive that there are written individual team determinations with regard to placement in the most integrated setting.

In spite of all this, the number of residents discharged from BSDC to integrated community placements has been very low and has stagnated over recent years. As of mid-October, BSDC had placed only two residents into integrated community settings in 2007. In the previous five years, BSDC placed a total of only 14 residents into the community – an average of less than three per year. Not a single resident was placed into the community in all of calendar year 2005. In the last 10 years, BSDC has never placed more than six residents in any given year into integrated, non-institutional settings. As a result, it is clear that team recommendations are not being implemented and that many BSDC residents who have been assessed as appropriate for community placement remain in the segregated institution.

The census at BSDC has slowly but steadily decreased in the past 10 years. In 1997, BSDC served 401 residents; as of mid-October 2007, BSDC served 322 persons. However, the number of residents has decreased not because of increased community placements, but, especially in recent years, almost exclusively due to resident deaths and facility transfers to other restrictive settings such as nursing homes or other institutions. Thus far in 2007, 11 residents have died and 15 residents were transferred to other restrictive settings; this accounted for over 95 percent of the changed census number from 2006. A very similar situation existed the previous year. There were 11 resident deaths and 10 discharges to other institutional settings; this accounted for over 90 percent of the changed census number from 2005. The emphasis on transferring residents to other restrictive settings is a relatively new phenomenon. For example, from 1997-2004, only three residents had been transferred to another restrictive setting; since then, 31 residents have been referred to nursing homes or other institutions.

The small number of community placements is troublesome because not all BSDC residents are difficult to place. While it may be true that some of those who live at BSDC may have unique care considerations and face more barriers to placement than others, this does not mean that they cannot be placed with appropriate protections, services, and supports.¹⁰

¹⁰ Shortly after our on-site visit, the State announced its intent to “right-size” the facility to serve fewer people at BSDC by determining if additional persons could be served in the community. There were no details as to how many residents might be impacted or when or where placements might occur.

2. Barriers and Impediments to Community Placement

It appears that the opposition of certain parents and guardians is a significant barrier at times to effecting placement determinations. As of March 2007, the facility estimated that about 76 percent of BSDC guardians were not willing to consider community placement options. We learned that if a family member or guardian expresses opposition or lack of interest in community placement, the resident's Personal Plan invariably concludes that continued stay at BSDC is appropriate at this time, regardless of the team's separate determination on the appropriateness of community placement. This is true for a wide variety of BSDC residents, including those who enjoy community visits, are stable, are very capable, and have team goals to be more independent.

It appears that few meaningful activities are undertaken to help support placement efforts from BSDC as long as a parent or guardian is not in agreement. This is unfortunate, especially in those cases where BSDC residents have expressed an eagerness to leave the facility to live in the community, but cannot leave because of outside opposition. The State has recognized that BSDC guardians sometimes make decisions that do not support a resident's choices and goals, which often include community placement.

Much of the opposition appears to be driven by unfounded fears or a lack of knowledge about community alternatives that are or could be developed. The State has not done enough to work with parents and guardians to better educate them about community options so as to better ensure that their decisions about placement are truly informed ones. Indeed, BSDC staff informed us that it was their belief that parents and guardians would be more open to community placement if the State could provide them with more information and tangible assurances of safety. The State has not done enough to create forums where family members and guardians can ask questions, share information, and exchange transition success stories and how to overcome placement challenges. The State has not done enough to facilitate on-site visits to successful community homes. Moreover, the State has not done enough to alert families and guardians about new community provider home openings as they become available.

Another significant barrier is the lack and/or perceived lack of available community resources, including inadequate community provider expertise and capacity. This is especially significant for persons with involved health care needs and/or mental health/behavioral concerns. For example, the State does not appear to have developed viable integrated community alternatives to congregate nursing homes for persons with involved health care needs. Moreover, other than the few individuals impacted each year by the OTS program, which is discussed below, the State appears to provide inadequate expertise and support to placed individuals and to their providers when behavioral and mental health concerns and crises emerge. Especially in more rural parts of the State, there are relatively few psychiatrists with expertise in treating persons with developmental disabilities; local doctors may not have the experience to provide the psychiatric care needed for this often challenging population.

The community resources barrier appears to be having a tangible impact on whether appropriate BSDC residents must remain institutionalized indefinitely or whether they can move into more integrated community settings. Inadequate community resources, including inadequate community provider expertise and capacity, may slow transition efforts or render community placement unrealistic in some cases. Moreover, inadequate community resources, whether real or perceived, may chill families, guardians, and even BSDC teams from pursuing needed and worthwhile community alternatives for BSDC residents.

It is not clear that the State has done enough to identify and eliminate inadequate resource and capacity issues to meet the needs of BSDC residents who are appropriate for community placement. It appears that State efforts are not proactive, exhaustive, or in-depth in certain individual cases, especially when it is known that there is family or guardian opposition. For example, right now, BSDC appears to do nothing more than make a routine overture to the pertinent Regional Service Area¹¹ to determine whether adequate community resources exist or can be created to accommodate the resident in question. However, community providers typically do not create community homes and community resources, or even respond to State community service referral requests when the providers know that a parent or guardian is opposed to placement. Often, BSDC teams proceed with annual meetings without having received clear guidance from the Service Area on community resources or capacity. In this rather passive framework, it is unlikely that placement settings will be created for those BSDC residents who need or want to live in the community.

As a result of all this, an unfortunate cycle has been created: community resources are not developed because parents and guardians oppose and the parents and guardians oppose because sufficient community resources have not been developed. The State has not done enough to break this cycle by creating sufficient incentives for community providers to respond to service referral requests and to develop homes and resources to meet the placement needs of BSDC residents.

In the handful of instances each year where a BSDC resident is to be transitioned to the community, it appears that the transition and placement process is a considered and thoughtful one. The State reports that, in a series of transition meetings, there is an attempt to tailor the setting for the individual, address accessibility issues, and find a proper mix of clients for each home. The State reports that the transitioning individual makes a couple of pre-placement visits to the home to better ensure that it will be a good fit. The State reports little post-placement recidivism of discharged residents back to BSDC or to another institutional setting. This is one marker that the transitions have been successful, at least in the short-term. The State appears to place an appropriate emphasis on serving clients in smaller settings. For example, in the Southeast Service Area, over 95 percent of the clients with developmental disabilities live in

¹¹ The State of Nebraska's Health and Human Services System is administratively divided into five regions or Service Areas: Northern, Eastern (Omaha metropolitan area), Southeast, Central, and Western.

homes of five or fewer persons; the average number of persons in one setting is about two to three per home.

The individuals in these homes are supported by service coordinators who are to oversee the care and services they receive in the community. The richest average ratio is one service coordinator for every 23 clients in the Western Service Area; the poorest average ratio is in the Eastern Service Area at 1:30. There are no separate intensive service coordinator services with even richer ratios for persons with more involved and complex needs. It may be that vast geographical coverage areas, lack of community expertise and infrastructure, or other variables may necessitate richer ratios in order to meet the needs of the clients placed in the community. This is especially true for persons with behavioral issues and/or mental illness. Our psychology consultant noted that service coordinators are dispersed around the state and have limited time to advocate for the placement of a particular BSDC resident in the community and to support his or her retention there.

Problems with service-delivery and monitoring in the community appear to be having a direct, negative impact on the health and welfare of a number of clients with developmental disabilities who live in the Nebraska community system. During our visit, for example, we learned that a number of community clients have experienced significant problems associated with their inadequately addressed behaviors and/or inadequately treated mental illness. We learned that, in response to the rise or escalation of a new or ongoing behavior problem, too often clients are subjected to the administration of a large number of (often inappropriate) psychotropic or other medications. There is an issue as to whether particular community professional and other staff have the expertise needed to adequately treat persons with developmental disabilities who may have behavior problems or a dual diagnosis of mental illness. It seems clear that the State has not done enough to ensure that adequate behavioral supports and psychiatric care are provided to clients in the community. In particular, the State has not done enough to provide technical assistance or expert guidance to community teams, guardians, or providers to ensure that a solid professional is providing adequate input or actual direct professional services to placed individuals with problem behaviors or mental illness.

As referenced above, problems in the community like this have a negative impact on current BSDC residents as well. If the State does not identify and resolve such community problems, certain BSDC residents, who are entitled to adequate and integrated community placements, will not have a viable alternative to ongoing, unduly restrictive care at the BSDC institution. For example, BSDC teams may not recommend or take meaningful steps toward community placement if the teams suspect that needed protections, supports, and services are not in place in the community. Parents and guardians, influenced by anecdotes of poor community care, may not support or take affirmative steps to help implement team recommendations for placement. Finally, community providers may not accept certain BSDC residents with difficult behaviors or mental illness simply because the State has not provided the providers with the needed expertise, guidance, and support to meet the individualized needs of the person.

The State currently underutilizes expertise and resources at the various local and State colleges and universities that maintain programs related to providing protections, supports, and services to persons with developmental disabilities. Our psychology consultant observed that, during his on-site tour of BSDC, he met no students, which he found unusual. He noted that academic ties typically bring expertise, energy, as well as new and helpful research and practices to State programs and activities. Strengthening ties to such university programs would enable the State to tap into local expertise to help solve ongoing and outstanding problems, especially with regard to serving and supporting clients in the community, offering integrated habilitation and other community activities, treating behavior problems, reducing the use of restraints, providing psychiatric care and services, and providing proactive health care.

There does not appear to be any fiscal impediment to transferring BSDC residents to the community. On average, the cost to serve a person with developmental disabilities at BSDC is about twice the cost in the community. In fiscal year 2008, the annualized per diem cost to serve a resident at BSDC is over \$142,000.00; last year's support costs for persons on the State's comprehensive waiver (receiving both day and residential services, including service coordination, specialized services, room and board, and medical costs) was only about \$71,000.00.¹²

In spite of this, there is an ongoing concern that competition for limited community funds between BSDC residents and persons on the State's waitlist could pose a barrier or a yearly limit to placements from BSDC. As of September 21, 2007, Nebraska served a total of 3,499 persons with developmental disabilities in community services. In addition, there are 2,665 other persons with developmental disabilities on the State's waitlist for community services: 1,319 persons who receive limited community services and service coordination, and 1,346 persons who receive only service coordination.

3. Outreach and Intensive Treatment Services Program

The State has a small but worthwhile program at BSDC that helps keep persons with developmental disabilities from being institutionalized long-term. The State's Outreach and Intensive Treatment Services program is headquartered at BSDC and consists of two branches: the Outreach Treatment Services ("OTS") program and the Intensive Treatment Services ("ITS") program. The OTS program provides intensive consultation services on-site in natural community settings throughout the entire State of Nebraska for persons with developmental disabilities who are experiencing behavioral difficulties such as physical aggression, property destruction, and verbal aggression. About 80 percent of OTS-consulted individuals have had a dual diagnosis of mental retardation and mental illness. Over the course of several days, the OTS professionals identify the function and the context of challenging behaviors and then develop

¹² The Federal Government, through the Medicaid Program, pays for over half (about 58 percent) of the costs of institutional care at BSDC, as well as the costs of community care through the Medicaid Waiver program.

tailored and individualized recommendations, with specific interaction guidelines, intervention methods, and environmental modifications, for community teams to implement. OTS then provides limited follow-up contact for a short time thereafter.

The laudable goal at OTS is to support positive behavioral change to keep individuals as independent as possible, and in familiar surroundings in their homes in the community – away from more restrictive placements such as hospitals, nursing homes, psychiatric facilities, and other institutions like BSDC. OTS reports a high degree of success with good outcomes. OTS reports that the vast majority of local teams fully implement OTS behavioral and other recommendations. Most importantly, OTS reports that the individuals are typically able to maintain their community placement and other services, thus avoiding institutionalization. Such successes are very positive.

The ITS program provides short-term, in-patient behavioral treatment services for persons with developmental disabilities on a small, eight-bed unit on the BSDC campus. Invariably, all eight beds are full at any given time. The individuals served in the ITS often have been involved in serious behavioral incidents including physical aggression, verbal aggression, property destruction, self-injurious behavior, refusal to perform essential tasks, and elopement. ITS professionals try to stabilize individuals, identify the function and context of their challenging behaviors, and then develop and implement tailored and individualized recommendations to reduce these behaviors. We learned that it is common for the ITS to have to reduce and/or eliminate the use of certain inappropriate psychotropic medications that had been prescribed in the community. For example, in 2005, the ITS effected 144 psychotropic medication changes; in 2003, the number was 266. Typically, there are issues related to polypharmacy, dosage, and appropriateness of the medications. Ultimately, the ITS seeks to transport the person back to the community within about three to four months with a better individualized support/behavior plan supported by a proper mix of psychotropic medications, if necessary. The ITS assists with the transition so as to better ensure success in the community. The ITS then provides limited follow-up contact for a short time thereafter.

While overall this is a worthwhile initiative, there is a lingering concern that too many individuals do not return to the community after admission to the ITS, even though the State tries to avoid this. In 2005, 10 of 16 individuals discharged from the ITS were admitted to BSDC long-term; from 1997-2004, almost one-third of ITS admissions ended up at BSDC or another institutional setting. The ITS reports that some of these individuals had engaged in what would be considered criminal activity, and that this made them difficult to place. This may also account for the rather lengthy stays at the ITS; in 2005, the average length of stay was about six months, with one stay extending for 419 days. This undercuts ITS's role as a "short-term" program.

Both the OTS and the ITS are creative programs that appear to be having a positive impact on preventing certain individuals with developmental disabilities from being institutionalized long-term. If anything, these programs should be strengthened and expanded so that they reach more people. Indeed, since 1997, the ITS has involved an average of only 14

persons per year; as of mid-October, the ITS was on a pace to serve only 10 persons in 2007. OTS personnel have averaged only about three dozen community visits per year since 2000, and the number of client outcomes achieved has been rather modest – the OTS closed 44 cases in 2006 and only 19 cases in 2005. Moreover, neither of these programs appears to be large enough now to meet current needs. For example, as of October 15, 2007, there were 21 individuals identified as waiting to get into the ITS; several persons have been waiting for over a year. Many other persons could receive OTS services each year if the program had a larger capacity.

The State does not make enough of a concerted effort to identify systemic issues from the individual cases arising under the OTS and the ITS that may cause community placements to fail and place individuals at risk of institutionalization. The ad hoc approach adopted thus far to address individual community problems has not led to the identification and development of systemic solutions to prevent these problems from recurring for a much larger group of similarly situated persons with developmental disabilities. Such an approach could address outstanding concerns associated with community health care, behavioral and mental health issues, individual crises, provider frustration and failures, and resource limitations especially with regard to service delivery in rural areas.

4. Bridges

As referenced above, at any given time, about a dozen persons with developmental disabilities live at the newly-created Bridges unit in Hastings, Nebraska. The Bridges facility is a BSDC-affiliated program, but it receives no federal funds to operate. This program treats persons with severe behavioral problems and/or a dual diagnosis of mental retardation and mental illness. The Bridges is a more restrictive and confining facility, located on a rather isolated campus, and its residential unit is locked. Each resident has his or her own room on this unit. The State informs us that it has taken more restrictive measures here because the individuals served at Bridges typically have been involved in serious incidents, including alleged sexual assault, that led to the involvement of law enforcement. Indeed, we understand that a few residents at Bridges would be prosecuted if released from the program. It was clear that most of the residents of the Bridges facility likely would be in jail if not for this program.

In spite of this, facility staff have taken efforts to keep residents involved somewhat in the community. Staff informed us that each resident goes to the community about four times per month for an hour or two at a time. Typically, the residents are provided with 2:1 staffing. Staff acknowledged that lack of staff can sometimes pose a barrier to community visits. Apparently, the residents do well on the community trips and restraints are never needed. We understand that in the community, the residents are happier, less bored, and exhibit fewer problem behaviors. Staff informed us that they continue to pursue community alternatives for the residents, albeit with plans for heightened supervision and protections.

In order to help pave the way for possible placement, facility staff engage the residents throughout each day in various programs, including individual therapy, coping strategy exercises,

and social appropriateness programs. Vocational activities occur on a separate floor from the residential unit in the same building. There is a restraint room on the residential unit where residents are subjected, at times, to multi-point mechanical restraints during behavioral episodes. Given limited time and the logistics of conducting a full team review so far from Beatrice, we did not engage in an in-depth analysis of the adequacy of these programs and whether or not facility staff were adequately addressing the often very difficult problem behaviors that led to the residents' placement at Bridges. Nonetheless, it appeared that the staff knew the residents very well and were working diligently toward helping the residents to meet their needs.

III. MINIMUM REMEDIAL MEASURES

To remedy the identified deficiencies and protect the constitutional and statutory rights of BSDC residents, the State should implement promptly, at a minimum, the remedial measures set forth below:

A. Protection from Harm

1. Procure adequate direct care staff and other staff hours to meet the needs of the residents.
2. Ensure that residents are supervised adequately by trained staff and that residents are kept reasonably safe and protected from harm and risk of harm.
3. Develop and implement adequate policies and procedures regarding timely and complete incident reporting and the conduct of investigations of serious incidents. Train staff and investigators fully on how to implement these policies and procedures. Centrally track and analyze trends of incidents and injuries, especially fractures, lacerations, and injuries of unknown origin, so as to develop and implement remedial measures that will prevent future events. Include systemic recommendations in investigation reports and ensure the prompt implementation of remedial measures to prevent future occurrence of incidents and injuries.

B. Training, Habilitation, Behavioral Services, Restraints, and Psychiatric Services

1. Provide residents with adequate training, including behavioral and habilitative services, needed to meet the residents' ongoing needs. These services should be developed by qualified professionals consistent with accepted professional standards to reduce or eliminate risks to personal safety, to reduce or eliminate unreasonable use of bodily restraints, to prevent regression, and to facilitate the growth, development, and independence of every resident. To this end, the facility should take the following steps:
 - (A) Ensure that all residents receive meaningful habilitation daily. Ensure that there is a comprehensive, interdisciplinary habilitative plan for each resident for the provision of such training, services and supports, formulated by a qualified

interdisciplinary team that identifies individuals' strengths, needs, preferences, and interests. Ensure that the plans address the residents' needs, preferences, and interests in an integrated fashion that utilizes the individuals' existing strengths. Ensure that staff are trained in how to implement the written plans and that the plans are implemented properly.

- (B) Provide an assessment of all residents and develop and implement plans based on these assessments to ensure that residents are receiving vocational and/or day programming services in the most integrated setting appropriate to meet their needs. Ensure that there is sufficient staffing and transportation to enable residents to work off campus or attend off-campus programming or activities when necessary.
 - (C) Provide residents who have behavior problems with an adequate functional assessment so as to determine the appropriate treatments and interventions for each person. Ensure that this assessment is interdisciplinary and incorporates medical and other unaddressed conditions that may contribute to a resident's behavior.
 - (D) Develop and implement comprehensive, individualized behavior programs for the residents who need them. Through competency-based training, train the appropriate staff how to implement the behavior programs and ensure that they are implemented consistently and effectively. Record appropriate behavioral data and notes with regard to the resident's progress on the programs.
 - (E) Monitor adequately the residents' progress on the programs and revise the programs when necessary to ensure that residents' behavioral needs are being met. Provide ongoing training for staff whenever a revision is required.
2. Ensure that highly restrictive interventions or restraints are never used as punishment, in lieu of training programs, or for the convenience of staff. To this end, the facility should take the following steps:
- (A) Develop and implement a protocol that places appropriate limits on the use of all restraints, especially the use of physical holds and one-point, two-point, three-point, four-point, and five-point restraints, as well as the routine use of emergency chemical restraints. Ensure that only the least restrictive restraint techniques necessary are utilized, and, that restraint use is minimized.
 - (B) Ensure that ineffective behavior programs that may contribute to the use of restraints are modified or replaced in a timely manner. For those individuals subjected to chronic use of restraint associated with difficult behavior problems,

obtain outside expertise to help the facility address the persons' behavior problems in an attempt to reduce both the behaviors and the use of restraint.

3. Provide adequate psychiatric services consistent with accepted professional standards to residents who need such services. To this end, the facility should take these steps:
 - (A) Procure adequate psychiatry hours to meet the needs of the residents.
 - (B) Ensure that each resident with mental illness is provided with a comprehensive psychiatric assessment, a DSM-IV diagnosis, appropriate psychiatric treatment including appropriate medication at the minimum effective dose that fits the diagnosis, and regular and ongoing monitoring of the psychiatric treatment to ensure that it is meeting the needs of each person. Ensure that the psychiatrist(s) provide new assessments and/or revisions to any aspect of the treatment regimen whenever appropriate. Ensure that psychiatric services are developed and implemented in collaboration with facility psychologists and other disciplines such, as neurology, when warranted, to provide coordinated behavioral care.
 - (C) Ensure that psychotropic medication is only used in accordance with accepted professional standards and that it is not used as punishment, in lieu of a training program, for behavior control, in lieu of a psychiatric or neuropsychiatric diagnosis, or for the convenience of staff. Ensure that no resident receives psychotropic medication without an accompanying behavior program.

C. Health Care and Clinical Services

1. Provide adequate medical care, nursing, and therapy services consistent with accepted professional standards to residents who need such services. To this end, the facility should take these steps:
 - (A) Procure adequate medical care, nursing, and therapy hours to meet the needs of the residents.
 - (B) Provide each resident with proactive, coordinated, and collaborative health care and therapy planning and treatment based on his or her individualized needs.
 - (C) Establish a formalized mechanism for identifying each resident with nutritional and physical support needs, including but not limited to persons who are at risk of choking/aspirating, have swallowing difficulties, require assistance to eat or drink, or receive enteral feedings or are a candidate to do so.
 - (D) Ensure that a specialized and qualified interdisciplinary team proactively addresses nutritional and physical support needs for those residents who require

them. The team should meet regularly for review and should include, at a minimum, representatives from the disciplines of medical care, nursing, nutrition, dysphagia, and physical, occupational, speech, and respiratory therapy.

- (E) Develop and provide a comprehensive individualized assessment of each resident who is in need of occupational therapy, physical therapy, speech therapy, assistive technology, and mealtime and physical assistance supports. Ensure that therapists' assessments identify individualized functional outcomes for therapy supports and services.
- (F) Ensure that all residents with therapy needs identified through the assessment process receive appropriate supports and services according to generally accepted professional standards.

D. Serving Persons in the Most Integrated Setting

1. Provide services to individuals with developmental disabilities in the most integrated setting appropriate to their needs. To this end, the facility should take these steps:

- (A) Conduct and update reasonable interdisciplinary assessments of each resident to determine whether the resident is in the most integrated setting appropriate to his/her needs. Ensure that those performing these assessments have adequate information regarding community-based options for placements, programs, and improvement.
- (B) If it is determined that a more integrated setting would appropriately meet the individual's needs and the individual does not oppose community placement, promptly develop and implement a transition plan that specifies actions necessary to ensure safe, successful transition from the facility to a more integrated setting, the names and positions of those responsible for these actions, and corresponding time frames.
- (C) Develop and implement an initiative to address barriers to placement, including capacity and expertise issues in the community, especially related to providing integrated services to persons with behavioral and/or mental health concerns.
- (D) Monitor community-based programs to ensure program adequacy and the full implementation of each individual's habilitation and service plan.
- (E) Strengthen and augment OTS and ITS efforts to prevent long-term institutionalization of persons with developmental disabilities.

* * * * *

IV. CONCLUSION

The collaborative approach the parties have taken thus far has been productive. We hope to continue working with the State in an amicable and cooperative manner to resolve our outstanding concerns with regard to BSDC.

Please note that this findings letter is a public document. It will be posted on the website of the Civil Rights Division. While we will provide a copy of this letter to any individual or entity upon request, as a matter of courtesy, we will not post this letter on our website until 10 calendar days from the date of this letter.

Provided that our cooperative relationship continues, we will forward our expert consultants' reports under separate cover. These reports are not public documents. Although our expert consultants' reports are their work – and do not necessarily represent the official conclusions of the Department of Justice – their observations, analyses, and recommendations provide further elaboration of the issues discussed in this letter and offer practical technical assistance in addressing them. We hope that you will give this information careful consideration and that it will assist in your efforts at promptly remediating areas that require attention.

We are obliged by statute to advise you that, in the unexpected event that we are unable to reach a resolution regarding our concerns, the Attorney General is empowered to initiate a lawsuit, pursuant to CRIPA, to correct deficiencies of the kind identified in this letter, 49 days after appropriate officials have been notified of them. 42 U.S.C. § 1997b(a)(1). We would prefer, however, to resolve this matter by working cooperatively with you. We have every confidence that we will be able to do so in this case. The lawyers assigned to this matter will be contacting your attorneys to discuss next steps in further detail.

If you have any questions regarding this letter, please call Shanetta Y. Cutlar, Chief of the Civil Rights Division's Special Litigation Section, at (202) 514-0195.

Sincerely,



Grace Chung Becker
Acting Assistant Attorney General
Civil Rights Division

cc: The Honorable Jon Bruning
Nebraska Attorney General
Office of the Attorney General of Nebraska

Christine Peterson
Chief Executive Officer
Nebraska Department of Health and Human Services

John Wyvill
Director, Division of Developmental Disabilities
Nebraska Department of Health and Human Services

Ron Stegemann
Chief Executive Officer
Beatrice State Developmental Center

Joe W. Stecher
United States Attorney
District of Nebraska

**IN THE UNITED STATES DISTRICT COURT
FOR THE DISTRICT OF NEBRASKA**

UNITED STATES OF AMERICA,)	
)	
Plaintiff,)	
)	
v.)	Civ. No. 8:08CV271
)	
THE STATE OF NEBRASKA;)	
DAVE HEINEMAN, Governor of the State of)	
Nebraska, in his official capacity only;)	
CHRISTINE PETERSON, Chief)	
Executive Officer, Nebraska Department)	
of Health and Human Services, in her official)	
capacity only; JOHN WYVILL, Director,)	
Division of Developmental Disabilities,)	
Nebraska Department of Health and Human)	
Services, in his official capacity only;)	
RON STEGEMANN, Chief Executive Officer,)	
Beatrice State Developmental Center, in his)	
official capacity only,)	
)	
Defendants.)	
_____)	

SETTLEMENT AGREEMENT

The United States and the State of Nebraska agree to settle this matter on the terms and conditions set forth below in this Settlement Agreement.

I. LEGAL FRAMEWORK

- A. This case was instituted by the United States pursuant to the Civil Rights of Institutionalized Persons Act (“CRIPA”), 42 U.S.C. § 1997.

- B. This Court has jurisdiction over this action pursuant to 28 U.S.C. § 1345.

- C. Venue is appropriate pursuant to 28 U.S.C. § 1391(b).

- D. The United States is authorized to institute this civil action pursuant to 42 U.S.C. § 1997a and has met all prerequisites for the institution of this civil action prescribed by the statute.

- E. The Defendants are the State of Nebraska; the Honorable David Heineman, Governor of the State of Nebraska; Christine Peterson, the Chief Executive Officer of the Nebraska

Department of Health and Human Services; John Wyvill, the Director of the Division of Developmental Disabilities within the Nebraska Department of Health and Human Services; and Ron Stegemann, the Chief Executive Officer of the Beatrice State Developmental Center (“BSDC”). All individual Defendants are officers of the Executive Branch of the State of Nebraska and are sued only in their official capacities. The collective Defendants shall hereinafter be referred to as “the State.”

F. BSDC is an institution covered by CRIPA and is owned and operated by the State of Nebraska to provide habilitation and other protections, supports, and services to persons with mental retardation and/or other developmental disabilities. The State has authority and responsibility for the operation of BSDC and is responsible for the implementation of this Settlement Agreement.

G. On May 29, 2007, the Attorney General of the United States, by and through the Assistant Attorney General, Civil Rights Division, notified the Governor of the State of Nebraska, the Attorney General of the State of Nebraska, the Chief Executive Officer of the Nebraska Department of Health and Human Services, and the Acting Chief Executive Officer of BSDC, of his intention to investigate conditions of care and treatment of residents at BSDC pursuant to CRIPA.

H. Following an investigation, including an on-site tour of BSDC from October 15-19, 2007, on March 7, 2008, the Attorney General of the United States, by and through the Acting Assistant Attorney General, Civil Rights Division, informed the Governor of Nebraska, the Nebraska Attorney General, the Chief Executive Officer of the Nebraska Department of Health and Human Services, the Director of the Division of Developmental Disabilities within the Nebraska Department of Health and Human Services, and the Chief Executive Officer of BSDC, that the Attorney General had reasonable cause to believe that BSDC residents were being subjected to conditions that deprived them of their legal rights and of their rights, privileges, and immunities secured by the Constitution of the United States.

I. The parties agree that the care, conditions, and training provided to BSDC residents, including any individual who was a BSDC resident at the time the United States concluded its on-site tour of BSDC on October 19, 2007 (hereinafter “residents”), implicate rights that are secured and protected by the Constitution and laws of the United States. The parties entering into this Settlement Agreement recognize these constitutional and legal interests, and for the purpose of avoiding protracted and adversarial litigation, agree to the provisions set forth below.

J. The purpose of the Settlement Agreement is that the State will achieve and/or maintain desired outcomes for BSDC residents and ensure that they are provided them with the protections, supports, and services they need to ensure that their constitutional and statutory rights are protected. In entering into this Settlement Agreement, however, State officials do not admit any violation of the Constitution or of any law, and this Settlement Agreement may not be used as evidence of liability in any other legal proceeding.

K. This Settlement Agreement is not intended to create any rights in any person or entity not a party to it. Nothing herein is intended to waive any rights or claims with respect to third parties who are not parties to this Settlement Agreement.

L. The provisions of this Settlement Agreement, voluntarily entered into, are a lawful, fair, and appropriate resolution of this case.

M. The parties shall request that this Settlement Agreement be entered by the United States District Court for the District of Nebraska, and be enforceable as an Order of the Court.

N. Once entered by the Court, this Settlement Agreement is legally binding and judicially enforceable by the parties, and it shall be applicable to and binding upon all of the parties, their officers, agents, employees, assigns, and successors.

O. Except where otherwise specified, the State shall implement all provisions of this Settlement Agreement within 90 days of the filing of this Settlement Agreement with the Court.

P. The United States agrees to consult with State officials before seeking judicial enforcement of this Settlement Agreement. Throughout, the United States and the State will coordinate and discuss areas of disagreement and attempt to resolve outstanding differences. It is intended that the parties will pursue a problem-solving approach so that litigation and disagreements can be minimized and the energies of the parties can be focused on the task of meeting the needs of the residents and achieving the outcomes set forth in this Settlement Agreement. The State shall ensure that identified deficiencies, if any, are remedied promptly.

Q. The United States will have full access to residents, persons, employees, residences, facilities, buildings, programs, services, documents, records, and materials that are necessary to assess the State's compliance and/or implementation efforts with this Settlement Agreement. Such access shall include departmental and/or individual resident medical and other records. The United States shall provide reasonable notice of any visit or inspection, although the parties agree no notice shall be required in an emergency situation where the life, immediate health or immediate safety of resident(s) are at issue. Such access shall continue until this case is dismissed.

R. All provisions of this Settlement Agreement will have ongoing effect until the final dismissal of this action.

S. The parties anticipate that the State will have implemented all provisions of the Settlement Agreement within four years of its filing with the Court. The Court shall retain jurisdiction of this action for all purposes until the State has implemented all provisions of this Settlement Agreement and maintained implementation of all provisions for one year and until such time as this action is dismissed. The parties may agree to jointly ask the Court to terminate the Settlement Agreement prior to the end of the four-year term, provided the State has implemented all provisions of the Settlement Agreement and maintained implementation of all

provisions for one year. If the case has not yet been dismissed, the parties agree to ask the Court for a non-evidentiary hearing on the status of compliance on or near this four-year anniversary date. If the parties agree that there is non-compliance, or if there is a dispute about compliance, the parties will so inform the Court, and the Court may set additional hearing dates as appropriate. The parties may agree jointly at any time to allow for additional time to resolve compliance issues.

T. The parties and the Independent Expert agree that any documents produced pursuant to this Settlement Agreement may be shared only with the following: (1) the Court; (2) any expert(s) or consultant(s) selected or retained by the parties pursuant to this Settlement Agreement; (3) all counsel of record in this matter; (4) staff and clerical personnel working with counsel of record in this matter; and (5) United States and other governmental officials, as necessary, in order to carry out law enforcement responsibilities.

U. All parties and the Independent Expert shall be responsible for maintaining the confidentiality of records in their possession. Submissions to the Court that contain identifying information of residents (such as their full name, address, or social security number) shall be filed with the Court using codes or pseudonyms.

V. The State shall promptly notify the United States upon the death of any resident, including the name of the resident, the date of death, and a preliminary cause of death. The State shall promptly forward to the United States copies of any completed incident reports related to deaths, autopsies, and/or death summaries of residents, as well as all final reports of substantiated abuse and/or neglect investigations that involve residents. The United States may require additional written reports from the State regarding the State's compliance with the Settlement Agreement. The State will cooperate and comply with any such requests.

W. The parties reserve the right to withdraw consent to the Settlement Agreement in the event that the Settlement Agreement is not approved by the Court in its entirety.

X. The parties shall bear their own costs, including attorney fees.

II. ***OFFICE OF THE INDEPENDENT EXPERT***

A. ***Selection of the Independent Expert and Consultants***

1. The parties have jointly agreed that John J. McGee, Ph.D., shall be appointed as the Independent Expert to monitor the State's implementation of this Settlement Agreement.

2. In the event that Dr. McGee resigns, or in the event that the parties for any reason jointly agree to discontinue the use of Dr. McGee as Independent Expert, the parties shall meet or confer within 30 days to try to agree upon a replacement person to fulfill the duties of the Independent Expert. The parties shall jointly select a replacement. If the parties are able to agree on a replacement, they shall notify the Court of their joint selection. If the parties are

unable to agree on a replacement within 30 days of their first meeting or conference, they shall jointly petition the Court to make the selection. In this petition, each party will be permitted to propose the names of three alternate candidates for the position, from which the Court shall select the new Independent Expert. The parties shall submit the candidates' *curricula vitae*, along with other pertinent information regarding the proposed candidates at the time of the submission of the names of the candidates. The procedure described in this paragraph, if necessary, shall apply to the selection of all successor Independent Experts.

3. The parties agree that Dr. McGee may use consultants to assist in completing the duties of the Independent Expert. In collaboration with the Independent Expert, the parties shall meet or otherwise confer whenever necessary to agree upon which particular consultant(s) Dr. McGee shall use to assist in completing the duties of the Independent Expert.

4. Neither the Independent Expert, nor any consultant (person or entity) retained by the Independent Expert to assist in completing the duties of the Independent Expert, shall be liable for any claim, lawsuit, or demand arising out of the monitoring of this Settlement Agreement. This paragraph does not apply to any proceeding before this Court for enforcement of payment of contracts or subcontracts for monitoring this Settlement Agreement. The selection of the Independent Expert shall be conducted solely pursuant to the procedures set forth in this agreement, and will not be governed by any formal or legal procurement requirements.

B. Budget of the Independent Expert

5. The parties and Dr. McGee have agreed upon the annual budget for Dr. McGee's work as Independent Expert. The agreed-upon budget is attached.

C. Reimbursement and Payment Provisions

6. The cost of the Independent Expert, including the cost of any consultant to assist the Independent Expert, shall be borne by the State in this action. All reasonable expenses incurred by the Independent Expert or any consultant, in the course of the performance of the duties of the Independent Expert, pursuant to the attached budget of the Independent Expert, shall be reimbursed by the State. The State shall provide the office of the Independent Expert with access to clerical assistance, office space, and office supplies as necessary. The United States will bear its own expenses in this matter.

7. The State shall deposit \$100,000.00 into the Registry of the Court as interim payment of costs incurred by the Independent Expert. This deposit and all other deposits pursuant to this Order shall be held in the Court Registry Investment System and shall be subject to the standard registry fee imposed on depositors.

8. The Independent Expert shall submit monthly statements to the Court, with copies to the parties, detailing all expenses the Independent Expert incurred during the prior month. These statements shall include daily records of time spent and expenses incurred, and shall include

copies of any supporting documentation, including receipts. The parties shall have seven business days from the receipt of the Independent Expert's monthly statements to submit to the Court any comments on or objections to the statements. The Court will then review the statements and any party's comments or objections and order the clerk to make the appropriate payments to the Independent Expert. The clerk shall then make those payments within 10 days of the entry of the Order authorizing payment. Within 45 days of the entry of each Order authorizing payment, the Defendants shall replenish the fund with the full amount paid by the clerk in order to restore the fund's total to \$100,000.00.

D. **Responsibilities and Authority of the Independent Expert**

9. The Independent Expert shall have the responsibility and authority to independently observe, assess, review, and report on the State's implementation of and compliance with the provisions of this Settlement Agreement. The Independent Expert shall regularly review the protections, services, and supports provided to residents in their residential settings and day programs or other programs to determine the State's implementation of and compliance with this Settlement Agreement. The Independent Expert's evaluation shall include: regular on-site inspection of the residences and programs of residents, interviews with administrators, professional and direct care staff, contractors, and residents, and detailed review of pertinent documents and resident records. The Independent Expert shall conduct on-site inspections at least every quarter. The Independent Expert shall devote such time as is necessary to fulfill the duties and responsibilities of the Independent Expert pursuant to this Settlement Agreement.

10. Within 30 days of appointment, the Independent Expert shall consult with the parties and shall submit a written plan with regard to the methodologies to be used by the Independent Expert to assess the State's compliance with and implementation of the Settlement Agreement.

11. The Independent Expert will have full access to residents, persons, employees, residences, facilities, buildings, programs, services, documents, records, and materials that are necessary to assess the State's compliance and/or implementation efforts with this Settlement Agreement. Such access shall include departmental and/or individual resident medical and other records. Such access shall continue until this case is dismissed.

12. The Independent Expert may have *ex parte* communications with the parties at any time.

13. The Independent Expert shall confer regularly and informally with the parties on matters relating to compliance, and the parties envision that the Independent Expert may provide specific recommendations with regard to steps to be taken to come into compliance with the Settlement Agreement. However, the State retains the discretion to achieve compliance by any legal means available, and may choose to utilize methods other than those that may be proposed by the Independent Expert. The Independent Expert shall not be empowered to direct the State or any of its subordinates to take, or to refrain from taking, any specific action to achieve compliance with the Settlement Agreement. Conversely, no party or any employee or agent of any party shall have any supervisory authority over the Independent Expert's activities, reports, findings,

or recommendations. The parties do not intend for the Independent Expert to have the role of a “Special Master.”

14. At least every quarter, the Independent Expert shall submit to the parties a draft written report with regard to the State’s implementation efforts and compliance with the Settlement Agreement. The parties shall have 15 business days to submit a response to the report to the Independent Expert. The Independent Expert shall consider the parties’ comments and within 10 days of receipt of the comments shall submit a final report to the parties, making whatever modifications the Independent Expert deems appropriate in light of the parties’ comments. While the parties are reviewing the draft report and submitting comments, the State will take timely action to remedy any deficiencies cited by the Independent Expert. Only where conditions or practices pose an immediate and serious threat to the life, health or safety of a resident or residents, may the United States use the Independent Expert's draft report in a compliance action before the Court prior to the completion of the review and submission period set forth above.

15. So as to review issues related to this Agreement, the State shall promptly notify the Independent Expert upon the death of any resident, including the name of the resident, the date of death, and a preliminary cause of death. The State shall promptly forward to the Independent Expert copies of any completed incident reports related to deaths, as well as autopsies, and/or death summaries of residents. The State shall promptly notify the Independent Expert of serious incidents, including but not limited to allegations of abuse and/or neglect, incidents producing a serious injury, incidents involving prolonged physical and/or mechanical restraint, and incidents involving law enforcement personnel. The State shall promptly forward to the Independent Expert copies of all final reports of investigations that involve residents. The State shall provide advance notice to the Independent Expert, along with copies of discharge plans, for residents to be transitioned to the community or any other setting. The Independent Expert may require additional written reports from the State regarding the State’s compliance with the Settlement Agreement. The State will cooperate and comply with any such reasonable requests.

16. It is intended that the Independent Expert will pursue a problem-solving approach so that disagreements can be minimized and the energies of the parties and the Independent Expert can be focused on the task of meeting the needs of the residents and achieving the outcomes set forth in this Settlement Agreement.

III. **REMEDIAL MEASURES**

A. **REASONABLE SAFETY, PROTECTION FROM HARM**

Principal Requirement

1. The State has declared that the most important concern of the State Department of Health and Human Services is the safety and quality of life of its clients with developmental disabilities. To this end, the State agrees to provide residents with a reasonably safe and humane living environment which includes that the State shall: (1) protect residents from abuse and neglect; and (2) take effective steps to minimize or eliminate resident injuries and other significant incidents that may negatively impact their health, safety, and welfare.

Zero-Tolerance for Abuse and Neglect

2. The State shall take effective steps to ensure that residents are free from abuse and neglect. The State has announced, and shall maintain, a policy of “zero-tolerance” for abuse (including verbal, mental, sexual, or physical abuse) and neglect, whether from other residents or from staff.

3. The State shall provide effective, ongoing competency-based training to staff on recognizing and reporting potential signs and symptoms of abuse and/or neglect, and on the prevention of abuse and neglect of residents by staff. Such training shall include providing staff with an explanation of the definitions of resident abuse and neglect, explaining to staff that abuse and neglect are prohibited, explaining to staff the requirement to promptly report any suspected abuse or neglect, and advising staff of the potential consequences if they commit abuse or neglect or fail to promptly report witnessed or suspected abuse or neglect.

Adequate Staffing

4. The State shall maintain sufficient numbers of adequately trained professional and direct care staff on each shift to provide adequate protections, supports, and services to residents at all times.

5. On or before November 1, 2008, the State shall maintain sufficient staff in direct care positions so as to minimize or eliminate the use of overtime to meet resident needs. The State may address staffing issues by hiring additional staff and/or by reducing the resident census at BSDC. In order to address staff fatigue, the use of mandatory overtime and requiring that staff work double shifts (two consecutive eight-hour shifts) is disfavored. In order to increase continuity of care and the familiarity of staff with particular residents and their needs, the State shall minimize or eliminate the use of part-time “on-call” staff and “pulled” staff who are unfamiliar with the residents on a unit.

6. The State shall ensure that residents receive all protections, supports, and services from staff who are properly trained on how to meet their individualized needs. The State shall place a heightened focus on ensuring that part-time “on-call” staff and staff pulled from other units are properly trained on individualized resident needs before assignment to any particular unit.

7. The State shall adequately supervise and monitor staff and residents at all times to ensure that staff are continually working to address resident needs.

8. The State shall conduct a regular review of all resident injuries and “significant” incidents to determine if staffing concerns are a contributing factor; wherever this is the case, the State shall develop and implement prompt and effective measures to address the staffing concerns in order to provide adequate and sufficient staff to care for and supervise residents and to prevent otherwise avoidable injuries and incidents. “Significant” resident incidents include all instances of: alleged, suspected, and/or substantiated abuse and/or neglect; serious injury, including those of unknown origin; actual or attempted elopement from the facility; and death.

9. Before permitting any staff person to work with residents, the State shall investigate the criminal history and other relevant background factors regarding that staff person, whether full-time, part-time, temporary, or permanent, including regularly-scheduled volunteer staff with direct resident contact. The State shall screen and take appropriate action to protect residents if the investigation indicates that the person would pose a risk of harm to the residents.

Resident Incidents

10. The State shall take effective steps to minimize incidents that may adversely impact the health, safety, and welfare of residents. This includes all “significant” resident incidents, especially those incidents that result in serious injury to residents.

11. Whenever a significant incident (other than death) occurs, the State shall immediately take appropriate measures to protect the safety and well-being of the resident(s) involved, including procuring any necessary basic care and/or health care treatment.

12. An interdisciplinary team on each BSDC living unit shall meet to identify, discuss, and address individual and systemic issues that have arisen since the last unit team meeting, as well as any individual and systemic issues that may arise before the next unit team meeting. The team’s conclusions and action steps shall be conveyed across shifts to ensure continuity and consistency with regard to implementation efforts.

13. On or before January 1, 2009, the State shall develop and implement across all settings and shifts an integrated and coordinated incident management system. All resident incidents, including incidents that result in injury, shall be accurately and consistently documented. Documentation of each injury shall be kept in the resident’s file and in a central location, and all incidents and injuries shall be entered into a central database, which is capable of capturing the following information: the type of incident, the time the incident occurred, the location of the

incident, the resident(s) and/or staff involved in the incident, and the nature and severity of the injury, if any. The State shall develop and implement, within 90 days, a policy mandating that staff report all incidents in a timely manner.

Quality Assurance

14. The State shall develop and implement a comprehensive quality assurance program to track and analyze patterns and trends of incidents and injuries, including incidents and injuries of unknown origin. The State shall develop and implement prompt and effective measures to address patterns and trends that impact the health, safety, and welfare of residents, so as to minimize or eliminate their occurrence in the future.

15. The State shall place an emphasis on identifying and analyzing resident-to-resident interactions that create risk of harm and/or actual harm, and then develop and implement measures to address these risk factors to prevent residents from harming themselves or others. The State shall identify vulnerable residents who are at higher risk of harm, and develop and implement measures to minimize or eliminate potential risk factors. The State shall identify aggressor residents and develop and implement measures, in conjunction with behavioral and other interventions, to minimize or eliminate potential triggers for aggression.

Investigation of Significant Incidents

16. The State shall investigate all “significant” resident incidents. As referenced above, “significant” resident incidents include all instances of: alleged, suspected, and/or substantiated abuse and/or neglect; serious injury, including those of unknown origin; actual or attempted elopement from the facility; and death.

17. The investigation of each significant incident shall be accurate, thorough, and complete. Investigations are to commence at least by the next working day of the incident being reported, and shall be concluded within 30 days of the incident being reported, or, when material evidence is unavailable to the investigator, as soon as is practicable so as to eliminate any undue delay. Other than with regard to matters involving a criminal investigation conducted by law enforcement authorities, investigators shall conduct interviews of all necessary witnesses in a timely manner. Each investigation will result in a written report. Each investigation report shall include: a summary of the incident and investigation, a chronology of events, a summary of interviews with all relevant staff and residents who may have information about the incident, findings with a detailed discussion of the bases for the findings (including a reasoned analysis of witness statements, documents, and other evidence considered), and recommendations for corrective action, when necessary, with timeframes for completion. The State shall ensure that investigators are competent, experienced, and well-trained in conducting investigations of significant incidents.

18. The State shall develop and implement prompt and effective remedial measures to address the individual and systemic issues and recommendations associated with these

investigation reports. The State shall track the implementation of the remedial measures on an ongoing basis to ensure that outstanding issues are addressed and appropriate resident outcomes are achieved in each instance.

19. The State shall require staff, including supervisory personnel, to safeguard evidence associated with the significant incident.

20. The State shall require that all potential criminal matters are referred promptly to appropriate law enforcement authorities. When law enforcement authorities indicate an intent to proceed with a criminal investigation, any compelled interviews of State employees shall be delayed until those authorities issue a written declination to proceed with a criminal investigation.

21. The State shall immediately remove any staff member suspected of staff-on-resident abuse or neglect from direct resident contact until the conclusion of the investigation and submission of the written investigation report about the incident.

22. The State shall impose appropriate disciplinary and/or corrective personnel action where a staff person is determined to have caused or been responsible for abuse and/or neglect, and against any staff person who fails to report a significant incident to supervisory or other appropriate personnel in a timely or accurate manner.

B. PLACEMENT IN THE MOST INTEGRATED SETTING

Principal Requirement

23. In accordance with Title II of the Americans with Disabilities Act (“ADA”), 42 U.S.C. § 12132, and implementing regulation 28 C.F.R. § 35.130(d), the State shall ensure that each BSDC resident is served in the most integrated setting appropriate to meet each person’s individualized needs. To this end, the State shall actively pursue the appropriate discharge of BSDC residents from BSDC and provide them with adequate and appropriate protections, supports, and services, consistent with each person’s individualized needs, in the most integrated setting in which they can be reasonably accommodated, and where the individual does not object.

Appropriateness for Placement

24. It is the State’s determination that all residents of BSDC meet the essential eligibility requirements for placement and habilitation in integrated community settings. All residents can be served in integrated community settings when adequate protections, supports, and other necessary resources are identified as available by service coordination. The State shall ensure that this is clearly set forth in each resident’s written interdisciplinary team recommendation contained within each individual’s BSDC Personal Plan, or equivalent.

Resident Involvement and Choice

25. Throughout, each resident shall be involved in the team evaluation, decision-making, and planning process to the maximum extent practicable, using whatever communication method he or she prefers.
26. To foster each resident's self-determination and independence, the State shall use person-centered planning principles at every stage of the process. This shall facilitate the identification of the resident's specific interests, goals, likes and dislikes, abilities and strengths, as well as deficits and support needs.
27. Each resident shall be given the opportunity to express a choice regarding placement. The State shall provide residents with choice counseling to help each resident make an informed choice; the State will provide enhanced counseling to those residents who have lived at BSDC for many years.
28. If any resident opposes placement, the State will document the steps taken to ensure that any individual objection is an informed one. The State shall set forth and implement individualized strategies to address concerns and objections to placement.
29. Throughout the process, the State shall regularly educate residents about the community and the various community options open to them. Any written materials or presentations shall be easy for residents to understand.
30. The State shall provide each resident with several viable placement alternatives to consider whenever possible. The State shall provide field trips to these viable community sites and facilitate overnight stays at certain of the community residences, where appropriate.
31. Where family members and/or guardians have reservations about community placement, the State shall provide ongoing educational opportunities to such family members and/or guardians with regard to placement and programming alternatives and options. These educational opportunities shall include information about how the individual may have viable options other than living with the family members and/or guardians once discharged from BSDC. The State shall identify and address the concerns of family members and/or guardians with regard to community placement. The State shall encourage family members and/or guardians to participate, whenever possible, in residents' on-site, community home field trips.

Transition Plans

32. The State shall set forth in reasonable detail a written transition plan specifying the particular protections, supports, and services that each individual resident will or may need in order to safely and successfully transition to and live in the community. Such a transition plan shall be prepared on or before January 1, 2009, for each resident regardless of whether or not a suitable community placement is currently available.

33. Each transition plan shall be developed using person-centered planning principles. Each transition plan shall specify with particularity the individualized protections, supports, and services needed to meet the needs and preferences of the resident in the alternative community setting, including their scope, frequency, and duration. Each transition plan shall include all individually-necessary protections, supports, and services, including but not limited to: housing and residential services; transportation; staffing; health care and other professional services; specialty health care services; therapy services; psychological, behavioral, and psychiatric services; communication and mobility supports; programming, vocational, and employment supports; and assistance with activities of daily living. Each plan shall include specific details about which particular community providers, including residential, health care, and program providers, can furnish needed protections, services, and supports.

34. The State will continue to¹ emphasize the placement of residents into smaller community homes.

35. In developing these plans, the State will avoid placing residents into nursing homes or other institutional settings whenever possible. The parties recognize that nursing homes are often not well-suited to provide needed habilitation to persons with developmental disabilities. The State will develop and implement a systemic plan to develop, through the Home and Community-Based Waiver or otherwise, integrated community alternatives to nursing homes for all residents with unique or more intense and complex health care needs.

36. Each transition plan shall identify the date the transition can occur, as well as timeframes for completion of needed steps to effect the transition. Each transition plan shall include the name of the person or entity responsible for: commencing transition planning; identifying community providers and other protections, supports, and services; connecting the resident with community providers; and assisting in transition activities as necessary. The responsible person or entity shall be experienced and capable of performing these functions.

37. Each transition plan shall be developed sufficiently prior to potential discharge so as to enable the careful development and implementation of needed actions to occur before, during,

¹ The United States does not concede that the words “continue to” or “maintain” throughout this Settlement Agreement mean or imply that the State has already been meeting residents’ needs in each area.

and after the transition. This shall include identifying and overcoming, whenever possible, any barriers to transition. The State shall work closely with pertinent community agencies so that the protections, supports, and services that the resident needs are developed and in place at the alternate site prior to the resident's discharge.

38. The State shall update the transition plans as needed throughout the planning and transition process based on new information and/or developments.

39. In developing the transition plans, the State shall attempt to locate community alternatives in regions based upon the presence of persons significant to the resident, including parents, siblings, other relatives, or close friends, where such efforts are consistent with the individual's desires.

40. The State agrees to provide as many individual on-site and overnight visits to various proposed residential placement sites in the community as are appropriate and needed to ensure that the placement ultimately selected is, and will be, adequate and appropriate to meet the needs of each resident. The State shall modify the transition plans, as needed, based on these community visits.

41. Each individual transition plan shall establish a schedule for monitoring visits to the new residence to assess whether the ongoing needs of the individual are being met. Each plan shall specify more regular visits in the days and weeks after any initial placement.

Implementation of Transition Plans

42. For those residents who do not oppose community placement, the State shall implement, in an expeditious manner, the transition plans that can be reasonably accommodated, by transferring each resident to an adequate and appropriate alternative community setting pursuant to the details set forth in each transition plan.

Developing and Expanding Community Capacity

43. The State shall take effective steps to support and expand service and provider capacity in the community so as to better serve residents placed and to be placed in the community. This shall include, but not be limited to, developing community capacity with regard to: housing and residential services; health care and other professional services; specialty health care services; therapy services; communication and mobility supports; and psychological, behavioral, and psychiatric services.

44. Based on data and information gleaned, in part, from the State's Outreach Treatment Services ("OTS") and Intensive Treatment Services ("ITS") programs, the State shall develop and implement a plan with effective steps to expand and improve expert health care and expert psychological, behavioral, and mental health services in the community for community residents with complex health care needs, and/or behavior problems and/or mental illness. The intent of

the plan shall be to better meet residents' health care, behavioral, and mental health needs in the community, avoid crises marked by the escalation of health care and/or behavior problems, and to minimize or eliminate failed or troubled community placements due to poorly addressed resident behaviors and, thus, minimize or eliminate re-institutionalization.

45. To assist in this process, the State will develop and implement a plan on or before March 1, 2009, to utilize and/or expand the State's existing electronic information system/tele-health network to better meet the needs of persons with developmental disabilities, especially those living in more rural areas of the State. The plan shall address how to provide more immediate and better access to records and expert professionals, transmit lab results and radiological reports between health care and other professionals, better track quality of care, improve communication with local hospitals and specialists, and generally provide better proactive care and treatment through a more seamless continuum of care to enhance resident outcomes. The plan shall address how to conduct video-conferences among various health care providers at scattered locations to save time and the expense of travel, and to encourage, wherever appropriate, the use of video-consults/clinics between local physicians and other professionals with specialists at distant locations. The plan shall also address how to incorporate timely tele-trauma services for residents in crisis. In developing and implementing this plan, the State shall ensure that the security and privacy of resident information is safeguarded.

46. The State shall significantly expand its OTS program to address unmet needs in the community that place individuals at risk of short-term or long-term institutionalization at BSDC. The OTS program shall continue to support positive behavioral change to keep individuals as independent as possible, and in familiar surroundings in their homes in the community, and away from more restrictive placements such as hospitals, nursing homes, psychiatric facilities, and institutions.

47. The State shall continue to support its ITS program, but shall strengthen its focus on returning individuals back to appropriate community homes promptly after a short-term stay. The State shall maintain more restrictive criteria for admitting a person long-term to a congregate or institutional setting after a stay in the ITS.

Monitoring of Community Placements and Quality Assurance Measures

48. The State shall develop and implement a system, including service coordination services, to effectively monitor community-based placements and programs to ensure that they are developed in accordance with the individualized transition plans set forth above, and that the individuals placed are provided with the protections, services, and supports they need. These and other monitoring and oversight mechanisms shall serve to help protect individuals from abuse, neglect, and mistreatment in their community residential and other programs. The State's oversight shall include regular inspections of community residential and program sites; regular face-to-face meetings with residents and staff; and in-depth reviews of treatment records, incident/injury data, key-indicator performance data, and other provider records.

49. BSDC residents who are placed in the community shall be served by an adequate number of service coordinators to meet residents' needs. The State's service coordination program shall provide for various levels of follow-up and intervention, including more intensive service coordination for those residents leaving BSDC with more complex needs. To encourage frequent individual contact, residents leaving BSDC will be served by service coordinators that carry a caseload of no more than 25 individuals at a time. Service coordinators involved with individuals from BSDC with more complex and intensive needs will carry a caseload of no more than 20 individuals at a time. All service coordinators shall receive appropriate and adequate supervision and competency-based training.

50. The State shall provide prompt and effective support and intervention services post-placement to residents who present adjustment problems related to the transition process such that each resident may stay in his or her community residence when appropriate, or be placed in a different, adequate, and appropriate community setting as soon as possible. These services may include, but not be limited to: providing heightened and enhanced service coordination to the resident/home; providing professional consultation, expert assistance, training, or other technical assistance to the resident/home; providing short-term supplemental staffing and/or other assistance at the home as long as the problem exists; and developing and implementing other community residential alternative solutions for the resident.

51. The State commits to maintaining discharged residents in the most integrated community setting appropriate for their needs. Any admission or re-admission to BSDC will be considered short-term. If a resident is re-admitted to BSDC, the State shall document the basis for the re-admission and then conduct a prompt assessment to identify and resolve any factors necessitating the re-admission.

52. The State shall regularly collect, aggregate, and analyze data related to discharge and placement efforts, including but not limited to information related to both successful and unsuccessful placements, as well as the problems or barriers to placing and/or keeping residents in the most integrated and appropriate setting. On or before January 1, 2009, the State shall also collect, aggregate, and analyze community data for at least the past five years from its OTS program and its ITS program, which may reveal systemic problems or barriers to meeting individual consumer needs in the community. Such problems or barriers may include, but not be limited to insufficient or inadequate: housing, community resources, health care, behavior management and services, and meaningful day activities including supported employment. The State shall review this information on a regular basis and develop and implement prompt and effective strategies to overcome the problems and barriers identified.

53. The State shall regularly review various community providers and programs to identify gaps and weaknesses, as well as areas of highest demand, to provide information for comprehensive planning, administration, resource-targeting, and implementing needed remedies. The State shall develop and implement effective strategies to any gaps or weaknesses or issues identified.

C. **TRAINING AND BEHAVIORAL SERVICES, RESTRAINTS, AND PSYCHIATRIC CARE**

Training and Behavioral Services

Principal Requirement

54. The State shall provide adequate psychological and behavioral services, including skills training and positive behavioral support plans, to meet the individualized needs of each resident, especially those with challenging behaviors. These services shall be developed and implemented to ensure and protect residents' right to training sufficient to provide each resident a reasonable opportunity to enhance functioning, to grow and develop, to attain self-help and social skills needed to exercise as much autonomy or independence as possible, to prevent or decelerate both physical and psychological regression, loss of skills and functional status, and to ensure their reasonable safety, security and freedom from undue bodily restraint. To this end:

Individualized Assessments

55. The State has begun and will continue the process of conducting a new interdisciplinary evaluation of each resident to determine the specific areas in which each resident needs training. These interdisciplinary evaluations shall be completed for all residents on or before January 1, 2009, and shall be repeated for all residents at annual intervals, unless required more frequently by each resident's needs; residents with challenging behaviors will likely require interdisciplinary evaluations much more frequently than once a year.

56. This interdisciplinary evaluation shall include adequate behavioral assessments (including an individualized, formal functional analysis whenever appropriate) based on the input from the psychologists and an interdisciplinary team. A functional analysis is an assessment of an individual's behavior that includes: (1) a description of the behaviors(s); (2) the collection of empirical data; (3) an assessment of the behavioral intensity, frequency, duration, and severity; (4) an evaluation of the antecedents, consequences and function of the behavior(s); (5) an assessment of any medical, nursing, mental health or other conditions related to the behavior(s) so as to determine the medical, behavioral, mental health, environmental and/or other factors that may be causing each resident's challenging behaviors; and (6) the development of skills training, behavior support, and other procedures based upon the analysis. The psychologist's assessment and functional analysis shall be based on a first-hand, in-depth, observational analysis of each resident's behavior, and not primarily from data provided pursuant to a screening tool.

Skills Training and Habilitation

57. Based on this evaluation, the State shall develop and implement a professionally-based, individualized skills training and habilitation support plan for each resident and provide each resident with a minimum of five hours per day of off-residence skills training, in the community

whenever appropriate, derived from the resident's skills training and habilitation support plan, to meet the individualized needs of each resident. The skills training and habilitation support plans shall include real-life variables, in the community whenever appropriate, with outcome measures that will be meaningful to residents with an emphasis on providing training in functional contexts. Plans shall be developed and implemented with a focus on proactive skills building and an emphasis on reducing the use of restrictive interventions. Residents' needs for meaningful training shall be continually met.

58. In developing and implementing the skills training and habilitation support plans, the State shall provide residents with these services in the most integrated setting appropriate for each individual resident. The State shall emphasize involvement in and with the community, away from the BSDC campus, as much as possible and appropriate, according to each resident's individualized needs.

59. The State shall develop and implement an initiative to significantly increase community integration activities and opportunities for residents day-to-day, including: (a) community supported employment; (b) community day programming; (c) community volunteer activities; and (d) community business and recreational outings, including but not limited to grocery stores, pharmacies, restaurants, theaters, and places of religious expression. This initiative shall ensure that staffing, transportation, and other resources are adequate to meet the residents' needs for community integration activities and opportunities.

60. The State shall develop and implement an initiative to better engage residents in meaningful training and activity throughout each day, according to their individualized needs, when the residents are on-campus and/or on their living units. This initiative shall make better use of on-campus recreational facilities, such as at the Carstens Center.

Positive Behavioral Support Plans

61. For residents with behaviors, the State shall ensure that psychologists develop and implement positive behavioral support plans that include: (1) a detailed definition and identification of the specific, measurable, and objective behavior(s) to increase and/or decrease; (2) a description and incorporation of the individualized functional analysis; (3) a comprehensive discussion of how medical and/or psychiatric disorders impact behavioral problems; (4) the procedures for staff to follow to decrease the occurrence of the problem behaviors; (5) the skills and positive, adaptive behaviors (to include replacement behaviors) that will be taught and the procedures for teaching them; (6) environmental changes to promote the development of positive, adaptive behaviors; (7) individualized reinforcers and/or preferences as determined in accordance with the needs of each resident; (8) an individualized schedule of active treatment activities as documented in the resident's individualized plan that corresponds to the resident's treatment needs; and (9) an adequate data collection system that includes appropriate data collection procedures which, for residents with positive behavioral support plans, shall measure information about maladaptive and adaptive behaviors and the conditions under which they

occur, including, where appropriate, the frequency, intensity, severity, and duration of the behaviors.

62. In developing and implementing these positive behavioral support plans, the psychologists shall adequately document their clinical findings and the treatment hypotheses to be tested, and set forth how treatments are derived. The psychologists shall also document their rationale for using specific behavioral interventions.

63. The State shall ensure that psychologists write concise and simple-to-use positive behavioral support plans at a level that can be easily understood and implemented by direct care staff.

64. The State shall improve implementation of behavioral plans at the direct care staff level. As part of this initiative, in conjunction with outside consultants, as appropriate, the State shall provide regular and ongoing competency-based training to direct care and supervisory staff on how to properly redirect residents' behaviors pursuant to each resident's plan, without resorting to the undue use of planned or unplanned mechanical, physical, or chemical restraints.

65. Both skills training and positive behavioral supports shall be developed and implemented as part of a resident's overall individualized plan. The State shall ensure that there is effective coordination and integration of services and treatment modalities, including psychology, psychiatry, neurology, nursing, medical and health care, and other needed services.

66. On or before January 1, 2009, the State shall maintain an effective Behavior Intervention Committee review process for the development and implementation of positive behavioral support plans, with an emphasis on stringent review and approval of restrictive interventions.

Monitoring and Follow-Up

67. The State shall develop and implement an effective system to regularly monitor each resident's skills training and positive behavioral support plans. The monitoring of the skills training and positive behavioral support plans shall produce prompt and effective follow-up action to ensure that: (a) the direct care staff are effectively implementing the skills training and behavior support plans, (b) the skills training and behavior support plans are effective and producing training and treatment outcomes specified in each resident's plan, and (c) where the residents are not making progress, the skills training and behavior support plans are modified appropriately and whenever necessary, and implemented promptly thereafter.

68. This monitoring system shall include tracking of systemic and individual outcome measures, with variables including, but not limited to: the incidence of resident behaviors, the use of restraints, the use of emergency procedures, and the implementation and monitoring of behavior plans. The State shall promptly and effectively address any systemic or individual problems identified through monitoring.

Priority Group

69. Based on the assessments and the monitoring, the State shall create a list of behavioral priority residents for heightened and enhanced attention and focus. This priority group shall consist, at least, of those residents who have already had a planned or unplanned mechanical, physical, or chemical restraint, those residents with a dual diagnosis of mental illness, those residents with significant or challenging behavior problems, as well as those residents who sustain or cause frequent injuries or are at risk of serious harm due to their behaviors.

70. In close consultation with outside consultants, as appropriate, the State shall prioritize these residents for the development and implementation of alternative and/or more tailored and intensive protections, supports, and services, where appropriate, through augmented and enhanced skills training and habilitation, positive behavioral supports, mental health care, and other interventions and treatment modalities, including an increased emphasis on community living and/or more structured, meaningful, and integrated habilitative activities in the community. These protections, supports, and services shall meet the resident's individualized needs without relying on the use of restraints. The intent here is to minimize or eliminate the triggers for behaviors, minimize or eliminate the behaviors themselves, and minimize or eliminate the use of restraints.

71. The steps necessary to achieve such positive outcomes for the residents in this priority group may include: daily interdisciplinary team meetings, regular contact with outside consultants, as appropriate, close observation of the residents and their staff, daily competency-based training of staff with regard to how to properly implement needed interventions, regular revision of plans and approaches, changes in the living environment, more frequent contact with people in the community in normal settings, and more meaningful and engaging day activities in the community.

Restraints

72. The State shall ensure that all residents are free from unreasonable restraint. The State shall develop and implement effective measures to minimize significantly or eliminate entirely the use of mechanical, physical, and chemical restraints on BSDC residents. The State shall ensure that restraints are not used as punishment, in lieu of habilitation, skills training and behavior support plans, or for the convenience of staff. Any restraint used will be the least restrictive form of restraint.

73. Restraints shall not be a part of any positive behavioral support plan and restraints shall not be used as a learning-based contingency to reduce the frequency of a behavior. Restraints may only be used for medical reasons or when there is immediate risk of harm to self or others (*i.e.*, to interrupt or terminate a seriously dangerous situation where injury could result). The State shall revise its policy definition of immediate risk of harm to self or others to ensure that the justified use of restraints is minimized. The State shall ensure that restraints labeled as

“medical” restraints are not, in fact, used for behavioral purposes or control. The State shall continue to prohibit the use of all prone physical and mechanical restraints.

74. In order to minimize or eliminate the use of restraints generally, the State shall ensure that the staff are adequately and appropriately implementing all aspects of each resident’s overall individualized plan, including aspects related to positive behavioral supports, skills training and habilitation, mental health care, and integrated community living and activities. The State shall ensure that the supervisory and professional staff are regularly monitoring the individualized plans and their implementation to ensure that the plans and their implementation are effective and producing the desired reduction or elimination in the use of restraints. Where plan modifications are needed to address a resident’s restraint usage, the State shall ensure that appropriate plan revisions are promptly developed and implemented.

75. The resident's psychologist shall begin the regular practice of reviewing, by the next working day, each use of mechanical, physical, or chemical restraint (excluding planned medical restraints), so as to ascertain the circumstances under which such restraint was used. The psychologist will conduct an analysis of what antecedents or circumstances may have prompted the behavioral escalation that led to the use of restraint. The psychologist shall analyze at least these variables: whether the behavior plan as written and/or implemented is effective in addressing the resident’s behaviors; whether the living environment is overly restrictive and segregated; whether the living environment is overly crowded and/or fosters conflict with too much exposure to other residents prone to behaviors; whether there is adequate skills training, habilitation, and/or meaningful community activities throughout the day; and whether the resident is receiving adequate and appropriate treatment for his or her mental illness. The psychologist will then promptly develop, and the staff will implement, individualized measures to minimize or eliminate such antecedents or circumstances.

76. If any resident is subjected to three or more restraints within a 30-day period, the State will convene a meeting of the resident’s interdisciplinary team, including the psychologist, to conduct a comprehensive review of the effectiveness and appropriateness of the resident’s existing protections, supports, and services. This team meeting shall take place on the first working day following the third restraint. The team meeting shall include the input and analysis of outside consultants whenever possible. The team shall promptly develop, whenever necessary, alternative and/or more tailored and intensive protections, supports, and services that meet the resident’s individualized needs, but that do not rely on the use of restraints. The team shall make specific recommendations and shall document these recommendations in the resident’s record, making changes in the resident’s individualized plan whenever necessary. These recommendations in the revised plan shall be implemented promptly and properly to meet the resident’s plan.

77. The parties anticipate that the use of mechanical, physical, and chemical restraints at BSDC will become a very rare occurrence. When utilized, however, staff shall take the following steps and precautions:

- a. provide immediate notification to an on-site supervisor upon the use of any restraints;
- b. provide notification to and obtain the approval of a psychologist and/or nurse if any restraint is applied for longer than one hour, and upon each hour thereafter;
- c. ensure that a nurse provides a timely assessment that the restraint is being safely applied and is reasonably tailored to the resident's behavior;
- d. provide continuous monitoring of the resident while restrained to ensure safety; ensure that a nurse or senior supervisor monitors and documents the residents' vital signs, respiration, circulation, and mental status at least every hour the resident is restrained; release every restrained limb from restraint, examine it for bruising and skin tears, and allow exercise of the limb at least ten minutes every hour; provide the restrained resident with an opportunity to eat, drink fluids, and toilet, as needed; provide every resident in restraint with continuous one-to-one supervision; and
- e. release every restrained resident from restraint as soon as the resident is determined not to pose an immediate risk of harm to self or others.

78. The State shall ensure that staff are adequately trained on the proper use of restraints.

79. The State shall document each use of mechanical, physical, and chemical restraint, including the date and time of use, the events leading to the restraint, the exact type of restraint or procedure used, as well as the length of time it was used. Documentation of each use of restraint shall be kept in the resident's file and in a central location.

80. The State shall ensure that chemical restraints meet appropriate levels of approval and oversight by a psychiatrist, psychologist, and physician prior to their administration. Staff shall collect adequate data on the effects, as well as adverse side effects, of each individual administration of such medications. The psychiatrist, psychologist, and physician shall consider the data collected when making future clinical intervention decisions. The State shall prohibit the use of standing PRN or "stat" orders for chemical restraints.

Psychiatric Care

81. The State shall provide adequate and appropriate routine and emergency psychiatric and mental health services to meet the individualized needs of each resident. These services shall be developed to ensure and protect residents' rights.

Adequate Psychiatry Hours

82. On or before October 1, 2008, the State shall procure additional psychiatry hours to meet the mental health needs of the residents. The psychiatrist(s) shall be well-respected with a demonstrated history of effectively meeting the needs of persons with developmental disabilities

and a dual diagnosis of mental illness. The State shall provide residents with enough psychiatry hours to enable the psychiatrist(s) to conduct thorough and complete evaluations, develop carefully considered differential diagnoses, order appropriately tailored treatments, and provide regular and sufficient follow-up monitoring to determine whether ordered treatments are, in fact, working to address the residents' underlying mental illness. If such treatments are not working, the psychiatrist(s) shall have enough time to conduct new evaluations, pursue alternative diagnoses and treatments, and monitor and follow-up again. The psychiatrist(s) shall have enough time to engage in this ongoing practice for all residents, including those residents with challenging behaviors associated with their mental illness. The psychiatrist(s) shall have sufficient time to see all residents frequently enough such that they are receiving effective treatment for their mental illness. The psychiatrist(s) shall have sufficient time such that no primary care physician, physician's assistant, or registered nurse is primarily responsible for providing psychiatric follow-up care.

Psychiatric Assessments and Diagnoses, and Mental Health Treatment

83. The State shall ensure that annually, or more often as needed, the psychiatrist(s) conducts a comprehensive assessment of each resident receiving psychotropic medication and each resident who has or may have a diagnosis of mental illness. The State shall ensure that for each resident assessed as having mental illness, the psychiatrist(s) documents a clinically justifiable, differential diagnosis consistent with DSM-IV-TR criteria. No resident shall have a current mental health diagnosis that is not clinically justified in the record.

84. The State shall ensure that the psychiatrist(s) develops and implements an overall mental health treatment plan for each resident with a diagnosis of mental illness, and provides ongoing monitoring and revision of the treatment plan. Any treatment must comport with the mental health diagnosis. The psychiatrist(s) shall ensure that there is proper coordination and integration of psychiatric services with other services and treatment modalities, including those in psychology, neurology, nursing, medical and health care, and other ancillary services.

Psychotropic Medication

85. On or before January 1, 2009, the State shall implement and maintain the following requirements with regard to the use of psychotropic medication:

- a. Prior to developing and implementing an appropriate treatment plan, the psychiatrist(s) shall review the current medication regimen of each resident to determine whether the type and dosage of the medication is appropriate and necessary, and then, if necessary, make any changes in the medication regimen.
- b. The psychiatrist(s) shall use psychotropic medication only as an integral part of the resident's individualized skills training and positive behavioral support plans.

- c. The psychiatrist(s) shall carefully review the medication regimen of residents where current doses are above the generally accepted effective dose for any particular medication.
- d. The psychiatrist(s) shall consult with the assigned psychologist and interdisciplinary team to determine whether the existing skills training and behavioral support plans are appropriate and whether different programs or interventions should be developed to address the resident's index behaviors and symptoms so as to reduce or eliminate the need for psychotropic medications.
- e. The psychiatrist(s) shall consult with the resident's primary care physician, nurse, or other appropriate members of the resident's interdisciplinary team, to determine whether the harmful effects of the resident's mental illness clearly outweigh the possible harmful side effects of the psychotropic medication and whether reasonable alternate treatment strategies are likely to be less effective or potentially more dangerous than the medication.
- f. The psychiatrist(s) shall ensure that the decision-making process for titrating medications up or down is clearly and fully set forth in each resident's record.
- g. The psychiatrist(s) shall ensure that there is a clear and full justification for the use of any typical or "first-generation" anti-psychotic medications.
- h. The psychiatrist(s) shall take care to reduce or discontinue benzodiazepines and anticholinergic medications that have been used for longer periods of time than are justified by the resident's psychiatric diagnosis.
- i. The use of intra-class polypharmacy shall be minimized, and whenever it is used, the psychiatrist(s) shall fully justify its use in that resident's treatment plan.

86. The State shall better educate guardians about proper mental health care and address their concerns when medication changes are needed to meet residents' needs.

Monitoring and Follow-Up

87. The State shall develop and implement an effective system to ensure that the psychiatrist(s) regularly monitors the residents with mental illness whenever needed, and make changes, when warranted, in the residents' treatment plans. For those residents who receive psychotropic medication, this monitoring shall be face-to-face, and shall be conducted quarterly by the psychiatrist(s), or more often as necessary based on the residents' current status and/or changing mental health needs. The monitoring review shall include a review of any current psychotropic medication provided, as well as a review of the pertinent behavioral and other data. Whenever necessary, the psychiatrist(s) shall provide a psychiatric re-assessment and revision to the treatment plan, as appropriate, for each resident who: i) presents a significant adverse

change in symptoms/index behaviors; ii) an increase in significant injuries or incidents related to symptoms/index behaviors; or iii) is subjected to an increase in repeated restraint due to a significant adverse change in symptoms/index behaviors.

88. The State shall maintain an adequate system for detecting, reporting, responding to, and documenting any drug-induced side effects of psychotropic medication. The State shall provide effective competency-based training for staff that complete side effects monitoring forms.

Chemical Restraint

89. Consistent with the restraint section above, when psychotropic medication is used on an emergency basis, a supervisor shall be notified immediately, there shall be continuous monitoring of the resident after administration of the medication, and a physician shall observe the effect of the medication by personally visiting the resident or directing supervision by a registered nurse. A psychiatrist shall review the use within 24 hours of the order being written if there are multiple administrations of the medication or if more than one order is written for different medications. The psychiatrist shall develop and implement measures to help prevent the emergency use of psychotropic medication in the future.

D. HEALTH CARE AND RELATED SERVICES

Principal Requirement

90. The State shall provide residents with adequate, appropriate and timely preventive, routine, acute, and emergency health care, including neurological care, to meet the individualized needs of the residents. The State shall develop and implement policies to guide the delivery of general and preventative medical care to meet the needs of the residents and require appropriate physician participation in the interdisciplinary provision of services and the creation of residents' individualized plans.

Adequate Health Care Staffing

91. The State shall maintain sufficient numbers of adequately trained health care staff, including physicians and nurses, on each shift to provide adequate protections, supports, and services to residents at all times. The State shall take effective steps to reduce reliance on temporary or floating health care staff, who may not be as familiar with the particular needs of individual residents. The State shall place a heightened focus on ensuring that new and temporary floating health care staff are properly trained on individualized resident needs before assignment to any particular unit.

Medical Care

Health Care Assessments, Diagnoses, Treatments, and Follow-Up Monitoring

92. The State shall have a physician conduct comprehensive health care evaluations of all residents, and repeat at annual intervals unless required more frequently by each resident's condition. The assessments shall be sufficient to enable the physician to reach a reliable diagnosis, if applicable, for each resident. The State shall develop and implement a system to ensure that referrals and testing procedures are completed and results are placed in the residents' medical record in a timely manner. For each resident assessed as having a health care concern or concerns, a physician shall document a clinically justifiable health care diagnosis for each of the resident's conditions. Based on the comprehensive medical assessment, the State shall ensure that a physician develops for each resident an integrated health care plan to address any health care conditions revealed through the assessment process. The State shall ensure that each resident's health care plan is implemented properly, day-to-day, to meet each resident's individualized health care needs.

93. To assist implementation efforts, the State shall take effective steps to improve communication among disciplines and departments at BSDC to eliminate confusion and fragmentation of care. To assist with this, the State shall continue to require medical staff members, including physicians and nurses, to participate in interdisciplinary team meetings. In addition, the State shall take effective steps to simplify and streamline charting, documentation, and record-keeping, with a goal of enhancing interdisciplinary communication and coordination to enhance timely service-delivery and continuity of care.

94. The State shall have a physician determine what specialized health care services, including neurological services, are required for each resident and ensure that each resident receives such specialized health care services in a timely manner whenever necessary to evaluate or treat each resident's health care problems.

95. The State shall develop and implement an effective system to regularly monitor each resident's health status and progress and develop and implement changes, whenever warranted, in each resident's health care plan. The State shall establish a health care quality assurance program that actively collects data relating to the quality of health care services, assesses these data for trends, initiates inquiries regarding problematic trends and individual issues, identifies and triggers corrective action, and provides ongoing monitoring to ensure that appropriate remedies are achieved.

96. The State shall develop and implement a plan to conduct regular internal chart audits with regard to the delivery of effective health care to residents. If any problems or concerns are identified as a result of any audit, the State shall promptly develop and implement corrective measures, both for individual and systemic issues.

Priority Group

97. Based on the assessments and the monitoring, the State shall create a list of health care priority residents for heightened and enhanced attention and focus. This priority group shall consist, at least, of those residents who have had a seizure or have a seizure disorder, have developed or are at risk of developing a bowel impaction or bowel obstruction, have aspirated or are at risk of aspirating, have developed a decubitus ulcer or skin breakdown or are at risk of developing a decubitus ulcer or skin breakdown, and have suffered a fracture or are at risk of suffering a fracture, including those residents with osteoporosis. The State shall include in this priority group any other resident who is in an at-risk group or is at-risk of suffering an incident that would adversely impact his or her health.

98. In close consultation with outside consultants, as appropriate, the State shall prioritize these residents for the development and implementation of alternative and/or more tailored and intensive protections, supports, and services, where appropriate, that meet the residents' individualized needs. The intent is that the State will develop and implement strategies to provide proactive health care such that resident seizures, bowel impactions and obstructions, aspiration and aspiration pneumonia, decubitus ulcers and skin breakdown, fractures, and the adverse consequences of other at-risk conditions will be minimized or eliminated.

99. The steps necessary to achieve such positive outcomes for the residents in this priority group may include daily interdisciplinary team meetings, regular contact with outside consultants, as appropriate, close observation of the residents and their staff, daily competency-based training of staff with regard to how to properly implement needed interventions, regular revision of plans and approaches, and changes in the living environment.

Seizure Disorders

100. The neurologist(s) shall identify all residents currently receiving anticonvulsant medication, residents with an existing diagnosis of epilepsy, and residents who have had at least one seizure in the past two years, and provide them with a comprehensive evaluation using a detailed diagnostic work-up conducted by a neurologist, at least annually, or more frequently as required by each resident's condition.

101. The neurologist(s) shall ensure that those residents with refractory seizures, i.e., those having more than 10 seizures in one year, receive appropriate and effective neurological interventions.

102. The neurologist(s) shall document the rationale and need for anticonvulsant medication in all cases, with a special emphasis on those residents receiving anticonvulsant polypharmacy, and document whether the potential harmful effects of the anticonvulsant medication on a resident's quality of life outweigh the potential benefits of the use of the medication. The neurologist(s) shall ensure that it is still appropriate for each resident currently receiving anticonvulsant medication, but who has remained seizure-free for the past two years, to continue

to receive the anticonvulsant medication. For each resident receiving medications for both seizures and a mental health disorder, the psychiatrist(s), the neurologist(s), and the interdisciplinary team shall coordinate the appropriate and continued use of such medications. The use of intra-class polypharmacy shall be minimized, and whenever it is used, the neurologist(s)/psychiatrist(s) shall fully justify its use in that resident's treatment plan.

103. The State shall develop and implement a system that ensures the accurate and timely recording of seizures for each resident including the following information: the date and time of the onset of the seizure; the duration of the seizure; a description of the seizure; an indication as to whether or not the resident is conscious or unconscious; if unconscious, the onset of the unconsciousness and the duration of the period(s) of unconsciousness; any medical or other steps taken to control the seizure; and the resident's response to the intervention. All staff, including nursing and direct care staff, shall be provided with competency-based training in recognizing a seizure, describing the seizure and length of time it lasts, and recording that information in the resident's record.

104. The State shall develop and implement an emergency protocol for the proper treatment of status epilepticus and provide competency-based training to the staff on how to implement it.

Peer Review

105. On or before January 1, 2009, the State shall create a peer review system with regard to the provision of health care services to residents. The peer reviewers shall be independent and external to BSDC and shall include individuals who are not employees of the State Department of Health and Human Services. The peer reviewers shall be well-respected health care consultants who have a demonstrated history of effectively meeting the health care needs of persons with developmental disabilities. Peer review of the provision of health care shall take place at least once a year. The peer reviewers will review a limited sample of plans from each physician or other primary health care provider. The review will include a targeted review of plans for residents in the health care priority group. Promptly after each peer review, the State will develop and implement measures to address all individual and systemic issues identified in the peer review process.

Mortality Review

106. On or before November 1, 2008, the State shall create an independent and external mortality review committee, comprised of well-respected health care consultants who have a demonstrated history of effectively meeting the health care needs of persons with developmental disabilities. The members of the mortality review committee shall be independent and external to BSDC, and shall not be employees of the State Department of Health and Human Services. The consultants who serve on the mortality review committee may also serve on the health care peer review committee. The purpose of the mortality reviews is to identify and promptly resolve any preventable causes of illness and death so that other similarly situated residents will not suffer preventable illness or death.

107. The mortality review committee shall meet promptly after each resident death to address individual and systemic issues related to each death. The committee shall have full and complete access to pertinent health care records and other documents, physicians and primary health care providers, and staff. The committee shall conduct appropriate interviews, and review and discuss any necessary supporting documentation related to the course of care leading up to each death, including: the death incident report, the completed death investigation, documents from the resident's chart, any autopsies that may have been performed, and reviews from all pertinent disciplines.

108. The committee shall identify preventable causes of illness and/or death, if any, in each individual case. The committee shall make written recommendations for remedial action, whenever appropriate, with regard to individual and systemic issues related to the death. The State shall ensure the prompt and effective implementation of all of the committee's recommendations. The mortality review committee shall continue to monitor all recommendations for remedial action until they are implemented.

National Health Care Organizations

109. The State shall take effective steps to encourage health care staff to become more actively involved in national health care organizations, especially those that focus on providing proactive health care to persons with developmental disabilities. The intent of this provision is that more involvement and engagement with national health care organizations may lead to better health care for residents.

Nursing Care

110. The State shall provide residents with adequate, appropriate and timely nursing care to meet the individualized needs of the residents. Nurses shall perform their responsibilities by adequately identifying and assessing health care problems, developing and implementing appropriate interventions, monitoring and intervening to ameliorate such problems, evaluating the appropriate outcome for the problems, and keeping appropriate records of residents' health care status.

111. The State shall develop and implement policies to guide the delivery of nursing care to meet the residents' needs with regard to conducting assessments, frequency of follow-up, and documentation for changes in residents' health status. The State shall develop and implement policies that require nursing participation in the interdisciplinary provision of services and the creation of individualized nursing care plans as part of residents' individualized plans. Nurses shall participate as core members of the interdisciplinary team. These policies shall include a formal communication system to alert all team members and health care providers to changes in a resident's health status, and documentation of reasons for the discontinuation of any team recommendations.

112. Nursing interventions shall be developed and implemented whenever needed, and especially for the following situations: (a) when a resident sustains an injury; (b) when a resident is restrained; (c) when medications are administered; (d) for the ongoing care of a resident's tracheotomy tube; (e) when a resident has a skin care and/or positioning and/or nutritional and physical management plan; (f) when a resident has or is at risk of developing a decubitus ulcer; (g) when a resident is at risk of a bowel impaction or obstruction; (h) when a resident presents any other risk factor; (i) when a resident suffers a significant weight loss/gain or is at risk of significant weight loss/gain; and (j) when a resident is enterally fed.

113. The State shall develop and implement an effective system to regularly monitor the residents' health care outcomes and make and implement changes in the residents' nursing care plans and interventions whenever warranted given the residents' needs.

114. The State shall provide nursing staff with ongoing competency-based training with regard to the following: (a) appropriate documentation and description of a resident's status when the resident leaves the facility and upon the resident's return; (b) role of the nurse in the interdisciplinary team process; (c) functional programming and habilitation; (d) proper development and implementation of the nursing care plans; (e) proper documentation and treatment of decubitus ulcers, including the description and the stage of the ulcer; and (f) proper documentation and treatment of significant events.

115. The State shall develop and implement a nursing Performance Management Process to monitor nursing assessments and documentation. Where problematic trends are identified, the State shall timely develop, implement and monitor a corrective action plan given the residents' needs.

116. The State shall administer medications to residents safely and effectively. When a medication error occurs, the State shall investigate the error, document it and take appropriate corrective action, including supervision and training.

117. The State shall ensure that nurses and other health care and direct care staff observe proper infection control procedures.

118. The State shall develop and implement a policy on the proper procedure for emergency tracheotomy care and replacement that includes competency-based staff training. The State shall provide an adequate and appropriate replacement tube of correct size and length which is easily accessible to each resident with a tracheotomy.

119. The State shall develop and implement a protocol for documentation of caloric, protein, water, and/or fluid intake requirements to ensure that residents, including those who are enterally fed, are receiving the prescribed nutrition and fluid intake to meet their individualized needs.

Nutritional and Physical Supports/Therapeutic Interventions

120. The State shall provide each resident with effective, appropriate, and timely nutritional and physical supports to meet the individualized health care needs of each resident.

Interdisciplinary Nutritional and Physical Support Team

121. The State shall ensure that an interdisciplinary team qualified to address nutritional and physical support issues addresses residents' global nutritional and physical support needs. The State shall ensure that the team meets on a regular basis, and includes representation from various disciplines as required to meet the individualized needs of the residents including, nursing, a physician, nutrition, psychology, occupational therapy, speech therapy including a specialist in dysphagia, respiratory therapy, and physical therapy, as well as certain direct care workers from the particular resident's unit, and any other necessary specialists.

122. The team shall identify each resident who has a nutritional and physical support need, or nutritional support problem, including all residents who are at risk of choking and/or aspirating, have dysphagia, difficulty swallowing, chewing, or retaining, food or liquids, have had aspiration pneumonia or other recurrent pneumonias, all residents who cannot feed themselves, any resident who currently receives or is a candidate to receive a feeding tube, and any resident with other medical or health care problems related to nutritional and physical support.

123. After the team members contribute comprehensive assessment(s) of the resident's individualized needs to identify the causes for the nutritional and physical support problem(s), the team shall provide an analysis of the assessment(s) in a written comprehensive, coordinated nutritional and physical support action plan (hereinafter called "action plan") to meet the individualized needs of the residents and that adequately addresses the resident's positioning and nutritional support needs throughout the day. The analysis and action plan shall describe antecedents and interrelationships of the occurrence of physical and nutritional health risk indicators. The action plan shall be implemented for each resident and shall address proper mealtime/eating techniques and positioning of the residents during meals (including snacks), drinking, tooth brushing, dental exams, medication administration, bathing, nighttime/bedtime, and other routine activities that are likely to provoke nutritional and physical support problems. The plan shall include support strategies to anticipate, minimize, or remediate these concerns with written documentation of measurable, functional outcomes to be achieved.

High Risk Criteria, Oversight

124. The State shall develop and implement criteria by which residents at the highest nutritional and physical risk are identified and assessed by the interdisciplinary nutritional and physical support team with regard to nutritional and physical support needs on an ongoing basis. The State shall prioritize these residents for the development and implementation of alternative and/or more tailored and intensive protections, supports, and services, where appropriate, that meet the residents' individualized needs.

125. The State shall develop and implement a system to provide review and oversight of at-risk residents so that those identified as at highest risk may benefit promptly from comprehensive nutritional and physical supports. The system shall clearly define and document the oversight role with regard to ensuring the effectiveness of implementation strategies. The system shall develop and implement a methodology and clearly defined policies and procedures related to follow-up and documentation to ensure that individualized outcomes are achieved.

Meals, Eating, Drinking, Plan Monitoring

126. The State shall develop and implement a system to ensure that staff do not engage residents in any mealtime/eating practice that poses an undue risk of harm to any resident, including assisting a resident to eat or drink who is improperly positioned or aligned, assisting a resident to eat or drink while the resident is coughing or exhibiting distress, assisting a resident to eat or drink with bites that are too large and/or faster than he or she can safely chew or swallow food and/or liquids. The State shall ensure that non-ambulatory residents shall be kept in proper alignment and shall not be laid flat on their backs during or after a meal until sufficient time has passed to allow digestion of food and/or liquids.

127. The State shall systematically and routinely monitor the implementation of the plans to ensure that the direct care staff safely and appropriately assist residents to eat and position the residents, especially for those residents who are at risk of aspirating, and to ensure that residents' nutritional and physical support plans are working effectively to meet the individualized needs of the residents to ameliorate the residents' physical and nutritional difficulties. The State shall ensure that all staff follow the instructions for each resident contained on the resident's nutritional and physical support plans.

128. The State shall develop and implement a system to ensure that staff assist residents with proper head alignment and other techniques during tooth-brushing, dental exams, and medication administration to minimize aspiration risk. The State shall ensure that there is proper coordination with dental and nursing personnel to accomplish this, and ensure that staff use proper infection control techniques during tooth-brushing to minimize risks of cross-contamination.

129. The State shall ensure that residents who use a feeding tube are fed through the tube only when medically necessary. The State shall evaluate and document the continued appropriateness of the tubes on a regular basis, and, where appropriate, develop and implement plans to return residents to oral eating and drinking. The State shall ensure that residents who take nutrition through a tube are provided with proper postural alignment and with adequate supervision to intervene whenever needed, especially if the resident is coughing during a tube feeding.

Therapy and Related Services

130. The State shall provide each resident with adequate, appropriate and timely occupational therapy, physical therapy, speech therapy, assistive technology support and physical assistance

support services to meet the individualized needs of the residents, to enhance the capacity of the residents to function, and to help the residents live safely and as independently as possible.

Assessments

131. The State shall identify and provide a comprehensive assessment of all residents who are in need of occupational therapy, physical therapy, speech therapy, assistive technology and physical assistance supports. Such assessments shall address: diagnoses and/or description of significant health care issues; health risk indicators; orthopedic concerns; musculoskeletal status, posture, functional mobility; functional performance of activities of daily living; communication; impact of health care issues on performance and therapeutic intervention; description of current therapeutic supports, which include mealtime, positioning and alignment, and assistive technology; and shall include baseline measurements where appropriate. Comprehensive assessments shall include analysis of findings to provide a rationale for recommendation and intervention strategies.

132. The State shall conduct a comprehensive assessment of all residents who use mobility, alternative/ therapeutic positioning, or other assistive technology supports (hereinafter, in this section, called "supports"). These assessments shall be completed in an interdisciplinary manner, including appropriate therapy staff and other appropriate staff, as well as direct care staff persons who know the resident well. Such assessments shall occur as frequently as needed to meet the individualized needs of the residents.

Implementation

133. The State shall develop and implement occupational therapy, physical therapy, speech therapy, assistive technology and physical assistance supports for all residents in need of such services as an integral part of the residents' individualized service plans. These supports shall have functional outcome goals and expectations that are measurable and which shall be implemented so as to document observable changes in a resident's function as a result of therapy intervention. The State shall conduct a comprehensive review of any existing occupational therapy, physical therapy, speech therapy, assistive technology or physical assistance supports for residents and determine whether these supports adequately meet the needs of the residents and are working as intended. The State shall develop and implement new or modified individualized service plans to meet the individualized needs of each resident identified in the assessments.

134. The State shall develop and implement the supports based on the comprehensive assessments so as to ensure that the supports and positioning are promoting good body alignment and functional health status. The State shall ensure that for residents with physical and nutritional problems, the supports mitigate the occurrence of aspiration and support other therapy goals for each resident based on the individualized needs of each resident. Proper supports and positioning are to be integrated into the resident's activities throughout the day.

Monitoring, Quality Assurance

135. The State shall systematically and routinely monitor the implementation of all of the aforementioned direct and indirect therapy supports to ensure that they are working effectively to achieve specific, measurable outcomes. The State shall develop and implement changes, whenever warranted, in the residents' supports and interventions to meet the individualized needs of the residents. The State shall adequately document direct therapy supports and interventions to justify initiation, continuation or discontinuation of such services to determine a resident's progress and the efficacy of treatment interventions. Direct therapy supports and interventions shall be documented and a monthly summary should identify the resident's status, progress and a comparative analysis of progress over time. Implementation of indirect therapy supports shall be documented at least quarterly per the individualized service plan.

Assistive Technology and Supports

136. The State shall develop and implement a quality assurance system for speech, occupational and physical therapy supports and services to self-monitor for quality improvement so as to achieve functional outcomes for residents.

137. Residents shall be provided with necessary identified assistive technology supports such as: (a) individualized, properly fitted seating systems that provide support and alignment for function that is optimal for that resident; (b) appropriate footwear while in such seating systems unless there is clear justification documented in the resident's record; and (c) seatbelts on wheelchairs and other mobility devices are appropriately positioned and adequately secured whenever appropriate to meet the needs of the residents. All supports shall be maintained in good working order and shall be repaired whenever necessary.

Alternate Positioning, Lifts and Transfers

138. The State shall develop and implement effective alternative positioning options for residents.

139. The State shall develop and implement a system to ensure that staff utilize appropriate lifting and transfer techniques.

Speech Therapy and Communication

140. With regard to speech therapy and communication, the State shall ensure that, on or before March 1, 2009, a qualified speech language pathologist with expertise in augmentative and alternative communication conducts comprehensive assessments of residents who need speech therapy and/or communication supports, develops and implements plans based on these assessments and monitors the implementation of the plans on an ongoing basis to ensure that they meet the individualized needs of the residents. The State shall ensure that such plans are reviewed and revised, as needed, but at least annually. The State shall develop and implement a

screening and evaluation tool and process designed to identify residents who would benefit from the use of alternative and/or augmentative communication devices or systems.

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I, on behalf of the undersigned parties, hereby execute and consent to the entry of this Consent Judgment.

Respectfully submitted,

UNITED STATES OF AMERICA, Plaintiff

Date: June 26, 2008

By: /s/ Grace Chung Becker
GRACE CHUNG BECKER [D.C. Bar #447313]
Acting Assistant Attorney General
United States Department of Justice
Civil Rights Division
950 Pennsylvania Avenue, NW
Washington, DC 20530

Date: June 26, 2008

And: /s/ Shanetta Y. Cutlar
SHANETTA Y. CUTLAR [Cal. Bar #169849]
Chief, Special Litigation Section
950 Pennsylvania Avenue, NW
Washington, DC 20530

Date: June 26, 2008

And: /s/ Benjamin O. Tayloe, Jr.
BENJAMIN O. TAYLOE, JR. [D.C. Bar #425691]
Special Counsel, Special Litigation Section
950 Pennsylvania Avenue, NW
Washington, DC 20530

Date: June 26, 2008

And: /s/ Richard J. Farano
RICHARD J. FARANO [D.C. Bar #424225]
MARINA MAZOR [D.C. Bar #479952]
Attorneys
United States Department of Justice
Civil Rights Division
Special Litigation Section
950 Pennsylvania Avenue, NW
PHB - Room 5020
Washington, DC 20530
Tel: (202) 307-3116
Fax: (202) 514-0210
richard.farano@usdoj.gov

Date: June 30, 2008

And: /s/ Joe W. Stecher
JOE W. STECHER, #17802
United States Attorney
District of Nebraska
1620 Dodge Street, Suite 1400
Omaha, NE 68102-1506
Tel: (402) 661-3700
Fax: (402) 661-3083
joe.stecher@usdoj.gov

THE STATE OF NEBRASKA, Defendant

JON BRUNING, #20351
Nebraska Attorney General
State Capitol, Room 2115
Lincoln, NE 68509-8920

Date: June 30, 2008

And: /s/ Jodi M. Fennner
JODI M. FENNER, #22038
Special Assistant to the Attorney General
Nebraska Department of Health
and Human Services
P.O. Box 95026
Lincoln, NE 68509
(402) 471-8609
(402) 742-2314 (facsimile)
jodi.fenner@dhhs.ne.gov

Date: June 27, 2008

And: /s/ Dave Heineman
DAVE HEINEMAN
Governor
State of Nebraska

Date: June 27, 2008

And: /s/ Christine Peterson
CHRISTINE PETERSON
Chief Executive Officer
Nebraska Department of Health
and Human Services
P.O. Box 95026
Lincoln, NE 68509

Date: June 30, 2008

And: /s/ John Wyvill
JOHN WYVILL
Director
Division of Developmental Disabilities
Nebraska Department of Health
and Human Services
P.O. Box 95026
Lincoln, NE 68509

WHEREFORE, the parties to this action having agreed to the provisions in the Consent Judgment set forth above, and the Court being advised in the premises, this Consent Judgment is hereby entered as the Order and Judgment of this Court.

It is so ordered, this 2nd day of July, 2008, at Lincoln, Nebraska.

/s/ Richard G. Kopf
HON. RICHARD G. KOPF
United States District Judge



**Progress Review and Long Term
Recommendations**
for the
Beatrice State Developmental Center (BSDC)
and the
**Nebraska Department of Health and Human Services,
Division of Developmental Disabilities**

"Our most important concern is the safety and quality of life for the clients."

April 2008

Produced by: Liberty Healthcare Corporation
401 E. City Avenue, Suite 820
Bala Cynwyd, PA 19004

Contact: Karen Peret, RN, Ed.D, CNAA/BC,
Vice President, Intellectual and Developmental Disabilities
(800) 331-7122

Liberty Healthcare appreciates the opportunity to work with Nebraska DHHS/Division of Developmental Disabilities to respond to deficiencies cited by CMS, develop and implement a plan of correction and to work to improve services for people who live at the Beatrice State Developmental Center. This report aggregates both the deliverables required by contract and significant additional work completed by the Liberty team and BSDC management during our 90-day tenure at BSDC. All of our efforts have been focused upon one contract goal as articulated by the Department's 5-Point Plan:

"Our most important concern is the safety and quality of life for the clients."

More specifically, all efforts are aimed at helping people achieve "everyday lives," reflecting the common hopes, aspirations and needs shared by most citizens:

CHOICE. . .People want choice in all aspects of their life including their relationships, budgets, how money is spent, their supports and services, their medical issues and planning.

QUALITY. . .People want quality of life as determined by them. People want quality supports and services to enable them to have a life that they want. When people pay for high quality supports, people expect to get high quality.

STABILITY. . .People want to feel secure that all changes in their lives are made only with their input and permission - "nothing about me without me."

SAFETY. . .People want to be safe at home, work, and school and in their neighborhood, as well as in all other aspects of their lives. People want services that ensure individual health and safety without being overprotective or restricting them.

INDIVIDUALITY. . . People want to be known for their individuality and to be called by their name. People want to be respected by having privacy of their mail, files, and history and being able to choose to be alone at times.

RELATIONSHIPS. . . People want relationships with family, partners, neighbors, people in the community such as pharmacists, hairstylists and grocers, support staff and with friends they choose.

FREEDOM. . .People want to have the life they want and to negotiate risk. People want others to use "People First" language and to have freedom from labels. People with disabilities have the same rights afforded to all citizens. They want to exercise the freedom of choice, to associate with people they choose, to move from place to place, and to use complaint and appeal processes.

SUCCESS. . .People want the freedom from poverty and a chance to be successful in the life they choose. Living independently with sufficient support to be successful and having expanded opportunities for employment with supports provided as needed.

CONTRIBUTING TO THE COMMUNITY. . .People want to be full citizens of the community, voting, working for pay or volunteering, participating in leisure and recreation activities, belonging to a religious community, owning or renting their own home, living among family and friends and not being segregated. People want to be recognized for their abilities and gifts and to have dignity and status.

COMMUNITY INTEGRATION. . .People want community integration in all aspects of their lives. People want to be able to use community resources, like banks and food stores, just as other people in the community do, without feeling left out because of a disability. Integration means both being in the community and having the opportunity to participate in all that the community has to offer; including generic resources that don't label people as "special".

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1. Executive Summary

Liberty Healthcare Corporation provided supports and services to Beatrice State Developmental Center from January 8 to April 20, 2008. During those 104 days, Liberty provided over twenty (20) specialists with many years' experience in regulation, management and training of systems for individuals with intellectual and developmental disabilities concerning governing body, active treatment, client protection, human rights, behavior services, therapy services, vocational services, medicine, nursing and community placement.

Liberty's goal is to create environments for people where they can be healthy and safe, can live lives that are meaningful and fulfilling and have their fundamental human rights honored and supported by people who care for and about them. Liberty's goal at the Beatrice State Developmental Center epitomizes that primary goal by assisting the dedicated staff at the facility in improving their systems and thereby improving the lives of those they support.

All observations and recommendations included in this report are, of necessity, static and reflect one point in time in a dynamic system, populated by people – both staff and residents – whose capabilities and needs change. We believe significant momentum towards positive change has been gained at BSDC in a relatively brief period of time.

During our time at Beatrice, Liberty's major systems accomplishments included:

1. Developed and oversaw the implementation of corrective action plans and assisted in the writing of letters of credible allegation to abate four immediate jeopardy citations, which allowed the facility to continue to receive \$28 million in federal funding.
2. Instituted a new model of active treatment whereby professional clinical staff are directly and actively involved in assessing residents' needs, developing active treatment programs and training and monitoring the implementation of the active treatment plans by the direct care staff. This will not only improve active treatment but enhance team knowledge of people so safety can be maintained and enhanced and safer more efficient transition between living areas at BSDC and between BSDC and the planned community placement can be made.
3. Created a new position and senior level accountability by revising the Table of Organization such that all professional disciplines report to the same Deputy CEO whose sole responsibility is to drive active treatment and to model and direct a completely new approach to active treatment that integrates treatment into every-day lives and interactions.

4. Increased the accountability and effectiveness of the Team Leaders responsible for planning for and executing daily programs for people, by dividing the formerly over-extended and too diffuse role into two discrete roles: House Manager and QMRP (Qualified Mental Retardation Professional). This not only allows greater focus on active treatment systems but smoother, more efficient use of staff, management of overtime and other personnel matters such as supervision and discipline. This was accomplished with existing staff and no additional personnel cost, with only new job descriptions and retraining still to be finished.
5. Totally revised risk management systems from data aggregation focus to data interpretation where the emphasis is on understanding factors that create risk, prevention and a proactive approach leading to more meaningful reporting and subsequent reduction of residents' risks for injury.
6. Revised the on-call staff assignment system to improve deployment of augmentive staff and completely change how staff is assigned. The cumulative effect will be incremental reductions of duplication, reduction of overtime requirements and better resident supervision especially on second and third shifts. This was accomplished with a relatively simple change such that a central timekeeper assigns the work location of all on-call staff when they report to duty as opposed to relief staff choosing where they report, or reporting to a pre-assigned area.
7. Expedited, by engineering process streamlining in conjunction with clinical input, consolidation of three resident living areas allowing three homes to close and the reassignment of 15 extra direct support staff to understaffed areas.
8. Revised and strengthened the community placement process by involving the resident's interdisciplinary team in identifying the supports necessary for successful community living and re-assigned accountability for quality and efficiency of the placement process.
9. Developed and instituted a resident-centered process to facilitate transfers between living areas at BSDC.

2. Overview of the Issues

The problems at BSDC are complex and deep-seated. It is not a simple matter of filling chronic staff vacancies so that there are enough personnel to supervise the residents. There needs to be significant increases in all of the clinical specialties that are required by federal authorities to deliver services that will meet minimum standards for active treatment and client protection. More importantly, the staff themselves need to apply contemporary management practices and person-centered methodologies, to avoid imminent decertification by CMS and legal action by DOJ. Further BSDC need to engage in a thorough overhaul and updating of systems and methodologies in combination with intensive training and establishment of a full contingent of required clinical and residential staff. By investing appropriate funding and resources in BSDC now, the State can avert the loss of annual federal funding and further intervention by the U.S. Department of Justice, which could mandate changes in the future.

Initial development of the Plan of Correction: The State's first priority in seeking on-site positional leadership, training, and other services at BSDC was to attain compliance with CMS citations in four Conditions of Participation and thereby protect federal funding. Liberty's involvement at BSDC began with a request from the State for assistance in correcting the identified four areas of deficiency: Governing Body, Client Protections, Facility Staffing and Active Treatment. Within two days of the call, Liberty brought in two former CMS surveyors to address the situation. They were quickly followed by other Liberty specialists who applied their expertise to assess, correct and improve functions in the multiple domains of operation at the facility. The Plan of Correction was submitted to CMS within a few days and quickly approved after just a single revision.

A three-point plan for long-term success: After helping to address the immediate crisis, Liberty's on-site team at BSDC focused on developing an integrated long-term solution for the challenges at Beatrice State Developmental Center. Based on our root cause analysis of the issues at BSDC, Liberty has articulated four crucial areas for continued major improvement:

- 1) **Knowledgeable and skilled leadership** – BSDC needs an integrated team of experienced, top-level managers and clinical managers who have mastery of state-of-the-art methods and practices in IDD and know how to operate an ICF/MR that will be consistently compliant with federal regulations in delivering safe, high quality supports to the people of BSDC.
- 2) **Effective organizational structure and systems** – Effective leadership requires effective management structure and operational systems. In particular, the reorganized management structure at BSDC should be reinforced so that each interdisciplinary clinical team is actively engaged with the residents and direct care staff in developing individualized support plans, implementing the plans, training the

staff, and monitoring effectiveness. The clinical team should first be skilled in contemporary person-centered methods, especially behavior analysis and positive behavioral supports, and should work collaboratively with the direct care staff and residents for effective outcomes.

- 3) **Chronic shortages of staff** – Given its rural location and the unique demands of working with people with disabilities, BSDC has had a long-standing struggle to attract and retain personnel in numbers adequate to deliver basic daily operations. The shortages are especially acute with regard to direct care personnel, whose salaries may be too low to be competitive. There are presently over a hundred vacancies for direct care personnel alone. Both CMS and DOJ have pointed to deficiencies in nursing, psychiatry, neurology, staff physicians, PT, OT, SLP and behavior analysts. The long-term solution will require a more effective recruiting effort, a reduction in the number of residents to be served at the facility and streamlining the staffing functions to improve the efficient use of the resources that exist.

- 4) **Community placements** – As articulated in two points in the DHHS Five-Point Action Plan, it is important to empower a major shift of resources from facility-based to community-based support of persons with intellectual and developmental disabilities. As emphasized by the Nebraska DD Director and legislative testimony, this effort is consistent with national trends and judicial decisions, such as Olmstead, and offers a practical approach to remediation of resource concerns at BSDC. The State has articulated a goal to transition over 100 residents at BSDC into the community by the end of 2008. This goal is commendable in improving the quality of life of persons with disabilities in Nebraska and would, by reducing the census at BSDC, help relieve the chronic staff shortages that plague the facility. But this is an ambitious goal that requires careful planning and highly sophisticated methods to be successful. Many individuals have extremely complex medical needs involving multiple conditions and medications that exceed the capacities of traditional community providers. Moreover, in our experience, federal authorities will first require that DHHS address the lack of current community capacity and other barriers to such transitions, and then require the State to monitor community-based programs once individuals have been placed and to strengthen and augment efforts to prevent future needs for long-term institutionalization.

3. Progress Review and Recommendations to Address Core Functions

This section of the report contains the general rationale and recommendations for long-term interventions at Beatrice State Developmental Center. A separate management plan lays out specific strategic actions to implement the recommendations.

A. Governing Body

The “Governing Body” is, simply, the boss. It is the entity that is responsible for managing and operating the facility. It can be seen as the most important Condition of Participation because a CMS citation for *any* Condition of Participation automatically results in a citation for Governing Body. Typically, the Governing Body is the Superintendent or Board of Directors and the top executive positions, such as Medical Director, Clinical Director, Director of Psychology and Director of Nursing. The Governing Body oversees the development, implementation and monitoring of all policies, practices and procedures.

By quickly bringing in two former CMS surveyors who would know precisely what is needed to respond to the CMS deficiencies, Liberty’s on-site team spearheaded the rapid creation of a Plan of Correction that met CMS approval. Based on our assessments of various facility operations and the approved Plan of Correction, Liberty used additional clinical and managerial professionals to guide the implementation of the changes needed to comply with CMS requirements and protect federal funding at BSDC.

Liberty’s team worked with BSDC to identify the root causes of its current problems and to develop the systemic changes needed for a long-term solution. As noted above, four domains have been identified as most crucial to resolving issues at BSDC:

- Establishing knowledgeable and skilled leadership.
- Establishing an effective organizational structure and systems.
- Resolving chronic shortages of staff.
- Applying proven methodologies to transition large numbers of BSDC residents to live in the community.

The first two are fundamental aspects of the Governing Body function and are therefore preeminent in Liberty’s recommendations to address this core function.

Establish effective leadership at all levels: In addition to establishing an executive management team with specialized knowledge of contemporary ICF/MR operations, the various clinical managers should also be up-to-date with contemporary person-centered methodologies and be able to teach and disseminate the new culture and values to the staff

at all levels. Liberty, in conjunction with the State, established several new management positions: Deputy CEO of Active Treatment, Deputy CEO of Neighborhood Services, QMRP Manager, Day Services Manager, Campus Employment Manager, Community Employment Coordinator, Home Manager, Program Coordinator and Shift Supervisors to focus attention on and development of core active treatment services and the efficient, effective utilization of professional and direct support resources. Job descriptions were developed by Liberty for these positions and are awaiting Human Resource approval.

Organizational structure with direct accountability: Management structures and lines of authority should be re-organized and strengthened for greater accountability and effectiveness, especially in areas of greatest risk, such as client abuse, injuries, protection of rights, appropriate use of psychotropic medications and management of challenging behavior. Clinical support staff have been reassigned to the Active Treatment Services Division to promote more direct involvement of the professional staff with the residents for whom they provide services and the direct support staff who work day to day with those residents. Clinical support professionals will play a more direct role in analyzing residents' needs, developing active treatment programs to address those needs, training direct care staff in the methods necessary to implement those active treatment programs, in monitoring the direct care staff's implementation of the programs and in evaluating the residents' progress on a regular basis.

Reorganization of QMRP and House Manager functions: Unlike standard contemporary practices, BSDC used a model that combined the roles of QMRP and House Manager into one job position. There is an inherent contradiction in having the same person responsible for delivering services and judging the quality of those services. While this strategy may have reduced the number of staff positions on paper, it backfired by increasing the workloads to unmanageable proportions. Liberty recommended the division of QMRP and House Manager functions to come into compliance with contemporary standards of practice in the field. Although this has been accomplished by the date of this report, those new roles need to continue to be supported and strengthened by the facility management.

Clinical team should work in close collaboration with direct care staff: Under the previous structure, the interdisciplinary clinical staff had been isolated from the development of individual support plans for the residents and the direct care personnel who are tasked with implementation of the plans. The clinical team should be in the resident living areas with the direct care staff and have direct involvement with the people who live at BSDC. They should be continuously engaged in assessing residents' needs, training staff, implementing the interventions, monitoring effectiveness and readjusting the plan as appropriate. Toward this end, Liberty recommended and oversaw the beginning of a shift of professionals' office space to be closer to the residents in their living areas. This will promote greater professional staff and resident interaction and allow the professional staff greater insight into residents' issues and living environments.

Right-sizing staffing to each setting: In continuing efforts to maximize the albeit inadequate staffing resources, Liberty analyzed current resident needs for each unit and residential function to determine the appropriate number of staff by type to maintain a safe environment, active treatment and routine daily supports. This includes a plan, already in implementation, to redistribute staffing in conjunction with the consolidation of the residents in a reduced number of residential units. Thus far the result has been the closure of three resident living areas and the reassignment of fifteen (15) extra staff to underserved areas at no additional cost to the facility. As further community placement occurs, BSDC will need to periodically review the principles of consolidation that have been developed and apply them to the changing census.

Strengthen on-site training: Ongoing training is crucial to maintaining a skilled and motivated workforce. Instead of a model that shares training on a state-wide basis, BSDC needs its own dedicated training component. Training needs to be a point of emphasis, delivered by permanent on-site staff, and followed up with effective mechanisms for monitoring staff skills and competency. Liberty has recommended that BSDC initiate an on-site training director and at least two on-site trainers to focus on the training requirements of the federal regulations and appropriate clinical standards of practice.

Proactive Quality Improvement and Risk Management Systems: Liberty developed an integrated Quality Improvement/Risk Management/Utilization Review (QI/RM/UR) Plan for BSDC that will rigorously and continuously scan for high-risk and incident-prone activities and aid compliance with all applicable licensure, DOJ, and Medicaid certification requirements. Data about negative outcomes, such as injuries, abuse, and critical incidents, will be gathered promptly and applied proactively by the leadership team to improve systems and prevent recurrence.

Reduction of staff overtime: A wide range of strategies are already underway for elimination of mandatory overtime. These include:

- The re-evaluation of staffing needs by a Liberty-led committee determined the number of staff needed in each residential living area to provide a safe environment and to plan for the reassignment of current staff.
- The division of responsibility between a Home Manager and a QMRP will permit more focused management of direct care staff schedules, providing oversight and making staffing adjustments more effective and resulting in a reduced use of overtime.
- The implementation of consistent, even distribution of daily staff scheduling across shifts replaced the previous uneven scheduling pattern at BSDC. House Managers now change days off for vacant positions before posting them so that, as positions are filled, the distribution of days off will be more even, thus requiring less use of overtime on a planned basis.

- The closure of homes and reduction in census allowed for the redistribution of fifteen (15) Developmental Technicians (DT) to other homes that were understaffed. Through Liberty's leadership, this redeployment was accomplished. The result was that eleven (11) staff were reassigned to the day shift. Consequently, five (5) more homes will be at their minimum staffing level on the day shift. Three (3) staff were scheduled for redeployment to evening shift and one DT was scheduled for transfer to night shift.
- On-call staff have been re-directed to report to the shift timekeeper for unit assignment instead of selecting their own place to work at their own convenience.
- Another strategy for managing DT resources is the creation of a facility-wide weekly review of enhanced staffing. The Director of Psychology has been asked to establish a Committee to review the status of all residents who are provided intensive staffing, the most costly support for individuals. Without clinical oversight it tends to be provided whether needed or not and drains direct care staff resources from routine coverage.

B. Client Protection

As stated in the DHHS Five-Point Plan, the "most important concern is the safety and quality of life for our clients." The "Client Protection" Condition of Participation most directly addresses the importance of maintaining a safe living environment while protecting individuals from possible injury or maltreatment.

From reactive to proactive client protection: Presently, some staff at BSDC spend upward of two to three hours a day reviewing accident and incident reports, which reflects a greater focus on responding to problems rather than preventing them. In an effective operation, there should be little need for such an expenditure of resources. Liberty has improved the specificity of the incident review process to focus on more timely reporting, better analysis and follow-up. A section for documentation of the review and consideration of trends and patterns and development of a preventive action plan was added to the electronic form used by the Incident Review members. Liberty recommends that BSDC continue the "management by data" approach that proactively analyzes patterns and trends to develop systems and interventions that can prevent future incidents.

Improved risk management policies: Liberty has endeavored to introduce and revise the basic operational policies and procedures governing risk management, including:

- Liberty helped to organize an inter-departmental Task Force to systematically review and revise BSDC policies related to risk management, beginning with the policies governing the use of restraint and management of inappropriate behaviors, to be compliant with regulations and contemporary practices in the field.

- Liberty developed a draft policies and procedures for the Neighborhood Services Area Incident Review Team and the BSDC Management Incident Review Team.
- Liberty developed draft policy and tools on Individual Risk Assessments to move toward a proactive, preventive approach of assessing and addressing risk to each person before incidents and injuries.

Multiple training initiatives: Liberty developed and presented training initiatives to support the client protection condition of participation.

- Liberty developed training for leadership staff to familiarize them with the structure of the CFR, the survey process and the **fundamental tags** for Active Treatment and the other fundamental tags used by surveyors.
- Liberty developed training in **trend identification and analysis** to Team Leaders, Area Administrators, the Neighborhood Administrator and members of the Incident Review Team. This training was reinforced by providing individual **mentoring** on trending and patterns with selected Team Leaders.
- Liberty also demonstrated the preventive planning techniques with a **pilot program to prevent injuries**. Liberty's team helped the Director of Quality Improvement to design and implement a pilot program in five settings where the rate of scratches exceeded 25% of the total injuries.

In vivo analysis of current systems: In addition to administrative and managerial level reviews of policies and procedures, the Liberty team made many participant observations of daily operations and practice to inform recommended plans for improvement. Some examples include:

- Liberty attended and **evaluated effectiveness of key BSDC staff meetings**, including the Leadership Team, Incident Review Team, Investigative Review Team and Administrative Review meetings.
- Liberty initiated an **audit of all Incident Review Team actions** from February 7, 2008 to April 7, 2008 and shared results with the Quality Improvement Director.

Strengthen incident review procedure: Liberty reviewed and revised the incident review system and spearheaded a number of changes. First, Liberty showed ways to improve the specificity of the Incident Review process to focus on more timely reporting, more thorough analysis, and consistent follow-up. Our team also added mechanisms to the electronic form to improve documentation of the Incident Review, to incorporate active consideration of trends and patterns for future prevention, and to mandate actions as needed based on identified trends.

“Decentralize” Incident Review process: Prior to Liberty’s involvement and recommendations, BSDC used a single facility-wide committee to review all incident reports. This centralized organization prevented the ability to identify patterns of incidents or injuries that were specific to the specific units or homes at the facility (e.g., repeated falls and near-falls outside the bathroom during morning shower routine at Building C). Clinical staff shortages also prevented the participation of appropriate IDT members who are knowledgeable about individual residents. Removed from the immediate monitoring of events at the unit level, the centralized committee had too many reports to review and could do little more than catalogue events after the fact. By activating Incident Reviews at the unit level, the interdisciplinary clinical teams could identify risk patterns more quickly and interventions can be developed and implemented more quickly to prevent and reduce recurrence. Liberty has recommended this model and had developed a plan for its implementation. However, the BSDC CEO asked that the plan not be implemented and be put on hold until the Home Managers and the QMRPs have been in their new roles for a period of time.

Improve quality improvement tools: By incorporating QI tools and processes from the national scene, Liberty has strengthened the Quality Improvement function with more effective measures for monitoring and evaluation of the quality of services at BSDC, particularly the Condition of Active Treatment.

Abuse prevention: Liberty’s team has emphasized that effective anticipation of risk – rather than response to abuse events – should be the focus at BSDC. By introducing methodologies such as trending analysis, improving systems, and training initiatives, Liberty helped BSDC to prevent abuse and establish true accountability. Liberty developed several training programs for future use by BSDC trainers in quarterly abuse prevention efforts such as: Reporting Abuse, Identifying Potential Victims and Abusers, Abuse Prevention and Abuse Investigation Procedures.

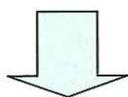
C. Facility Staffing

“Facility staffing” is another Condition of Participation that was cited for deficiencies at BSDC. It refers to the requirement of having appropriately trained and qualified staff in sufficient numbers to consistently provide basic functions at BSDC. The most acute and longstanding staffing deficiency has been the paraprofessional “direct care” staff who provide the hands on, around-the-clock supervision and support to the residents of BSDC. Numerically, direct care personnel typically constitute the largest job category for ICF/MR facilities. There are presently over a hundred vacancies for direct care personnel at BSDC, which means that the facility will remain in jeopardy of more CMS citations for inadequate facility staffing.

Given its rural location and the unique demands of working with people with disabilities, BSDC has had a long-standing struggle to attract and retain personnel in numbers adequate to deliver basic daily operations. Frankly, we believe that the State cannot resolve these chronic shortages without the will and resolve to make a fundamental change in approach at BSDC.

Either...

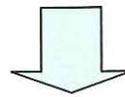
The census of BSDC should be reduced to numbers that can be effectively served with significantly fewer staff...



The solution is safely right-sizing the facility in combination with increasing community provider capacity to support successful reintegration.

and/or...

a qualified contractor should be empowered to bring in and retain large numbers of non-state employees to fill the large number of vacancies.



The solution is effective rural recruiting in combination with a large auxiliary private workforce with employment incentives.

Current efforts to “right-size” the facility: Although a significant number of residents at BSDC could be better served in community placements, we recognize that community provider capacity may be currently insufficient to support large numbers of such placements. Therefore, Liberty has endeavored to help “right-size” the facility with clinical and management strategies that reduce the demand for staff, including the safe reduction of one-to-one staffing and consolidation of living units.

- **Safely Reducing need for one-to-one supervision:** Frequent demands for one-to-one intensive observation place a tremendous strain on the workforce. When staff are assigned to shadow just one person, they are unable to perform their regular duties for the other residents. Liberty has tried to help safely but dramatically reduce the need for one-to-one supervision by (1) re-evaluating individual needs for more intensive or less intensive staff support; (2) delivering more training in contemporary methods of positive behavior management; and (3) establishing a review system for individuals who are receiving enhanced staffing. Liberty is also strongly urging the Department to (4) greatly increase the use of behavior specialists in the facility.
- **Consolidation planning:** Liberty’s team worked closely with BSDC staff to evaluate deployment and staffing patterns across units. They assessed the number of homes that can be safely staffed with existing resources and worked with BSDC staff to develop and implement a consolidation plan to reduce the number of units to be supervised. At present there are 23 homes remaining. Liberty’s team also improved the criteria and process for inter-home transfers as a precursor to further

consolidation of living areas. In this way, redistribution of residents to fewer homes can be done with sensitivity to their particular needs and levels of functioning. Consolidation needs to continue as further reductions in resident census occur during the next year.

Bring skilled behavior analysts to BSDC to reduce risk: Contemporary standards of practice in the field of intellectual and developmental disabilities require a strong role for behavior analysts. These IDD professionals apply their methodologies to manage challenging behavior (such as aggressive, inappropriate sexual behavior, self-injurious behavior, eating dangerous substances, yelling, etc.) without the need for physical restraints or inappropriate use of psychiatric medications, both of which pose serious liabilities to client health and human rights. In similar programs, behavior analysts have implemented individualized Protective Intervention Plans (PIPs) that are based on positive, empirically-validated behavior management approaches, which have virtually eliminated the use of physical and mechanical restraints and exclusionary timeout, while greatly reducing rates of client and staff injuries.

In the absence of effective behavior analysis services, there is increased risk for using both restrictive techniques and psychoactive medications to control challenging behavior. Liberty is urging BSDC to bring in a strong group of Certified Behavior Analysts to reduce risk. At present, however, there is a severe shortage of certified behavioral analysts in the State of Nebraska, particularly at Beatrice State Developmental Center.

Improved training and staff development: While the shortages of personnel at BSDC are of paramount concern, there is also need for major improvements in staff training, which is crucial to staff retention through improved job satisfaction. Training is also vital to the prevention of numerous risk events. Liberty's team initiated a range of strategies to improve staff training at BSDC, some completed and others requiring continuation.

- Train the leadership and clinical managers in contemporary IDD methods and standards as well as current CMS regulations, DOJ civil rights standards and other applicable surveyor standards.
- Help BSDC to establish its own permanent, on-site training specialists for a consistent, immediate availability of training.
- Update all training to incorporate contemporary methods, values and approaches to IDD.
- Revitalize in vivo training of direct care staff by requiring the clinical interdisciplinary team to be continually actively engaged in implementation of individual support plans and behavior plans.

More efficient use of current resources: As noted earlier, Liberty implemented several changes that will increase the effective use of current numbers of direct care personnel.

- The division of responsibility between a Home Manager and a QMRP which will permit more focused management of direct care staff schedules, providing oversight and making staffing adjustments more effective and result in a reduced use of overtime.
- A review of current schedules for even distribution of staff across days and across shifts. The previous pattern at BSDC had been uneven. House Managers were asked to change the days off for vacant positions before posting them so that, as positions are filled, the distribution of days off will be more even, thus requiring less use of overtime on a planned basis.
- Liberty analyzed staffing configurations for each unit and residential function to determine the appropriate number of staff by type to maintain a safe environment, active treatment and routine daily supports.
- On-call staff have been re-directed to report to the shift timekeeper for unit assignment instead of selecting their own place to work at their own convenience.

Established Need for Supervisory Structure: Even the most well trained of staff require supervision and guidance to perform their roles consistently and appropriately. Liberty developed a designated in-home supervisory structure on the second and third shifts to replace the current rotating system of the most senior person on duty for that shift assuming the supervisory responsibility. The designation of a stable, consistent supervisor should improve performance expectations of the direct care staff and increase the quality of the supports provided. Liberty developed justification and a job description for the Shift Supervisor position and presented it to the facility CEO and HR to pursue classification and creation of the position.

D. Active Treatment

The CMS Condition of Participation called “Active Treatment” is simply defined as helping people learn life skills to increase their own independence. It is about empowering clients as opposed to giving “treatment” to them. Residents are not able to learn self-sufficiency if staff are unnecessarily performing functions for them, such as feeding, cooking, dressing, bathing, or preparing meals. This can facilitate dependency and generate behavior problems because the residents may act out their feelings of resentment, frustration, helplessness, boredom and anger. Active treatment is therefore profoundly important in contemporary IDD person-centered approaches and is a key area needing improvements at BSDC.

Training initiatives and mentoring: On-site professionals at BSDC have developed a variety of training initiatives to bolster active treatment, including the following:

- Provided active treatment training to about 300 residential staff at BSDC that focused on promoting consumer self-sufficiency in the following areas.
 - Meal time (comprised of family style dining, increasing independence on the part of the individual, offering choices, and meal preparation).
 - Self-administration of medication.
 - Participation in community resources and activities.
 - Leisure activities.
 - Choice and decision-making.
 - Activities of daily living.
 - Staff/individual interaction skills.
 - Respect and dignity of individuals.
 - Money management.
- Developed a competency-based training module for Team Leaders and Human Services Treatment Specialists to improve the quality of individual program plans (IPP).
- Developed a training module to improve interdisciplinary team (IDT) processes.
- Provided competency-based “Active Treatment Meaningful Day” in-service training to more than 120 facility staff.
- Provided one-to-one competency based training to all 25 Team Leaders in the complete cycle of active treatment (assessment, IDT, and implementation, review and revision of the IPP).
- Delivered training in consumer rights and due process to the Team Leaders, Assistant Administrators and Neighborhood Administrator, which was followed by video-based repetition of this training to all staff at BSDC.
- Coached staff to support individuals in making personal activity choices based on their individual interests and relationship preferences.
- Mentored Team Leaders in fulfilling their roles in various team processes, such as IPP planning, IDT meetings, psychiatric clinics, investigations, trending incidents, and the Peer Review and Human and Legal Rights Committees.
- Mentored professional staff in how to write training objectives that are measurable, functional, and specific.

Direct assistance to BSDC staff in addressing deficiencies identified by CMS: Liberty's on-site staff worked closely with BSDC staff to rapidly resolve CMS issues in multiple areas, including:

- Developed a new Behavioral Support Plan (BSP) format that emphasizes positive replacement behavior as required by the federal regulations.
- Developed a new Quality Improvement Plan.
- Supported Team Leaders during the CMS survey process with pre-survey preparation, participating in the interviews, marshaling requested documents, and conducting post-survey debriefings.
- Assisted Team Leaders in addressing specific issues identified in the CMS Statement of Deficiencies, such as communication and vocational needs, repositioning for people in wheelchairs, implementation of IPP objectives, engaging people in active treatment, and integration of psychotropic medications in the IPP.
- Assisted BSDC staff in implementing supports for specific individual consumers identified in CMS Statement of Deficiencies, including one needing intensive behavioral supports.
- Instructed Team Leaders and revamped processes to enable IDT to proactively develop objectives to meet needs identified by the Speech and Language evaluations.

Creating more Active Treatment opportunities at BSDC: Liberty's on-site professionals provided consultation and direction to create and expand Active Treatment opportunities at BSDC, including:

- Expanded opportunities to work.
- Increased evening and weekend recreation/leisure opportunities with popular choices such as casino night, karaoke, relaxation spa, jazz social, and music events.
- Established Meaningful Days Committee to heighten awareness of the importance of Active Treatment.
- Explored enrollment of school age children into Beatrice public school system.

Promoting more real world employment opportunities: To facilitate the ultimate goal of greater self-sufficiency in the community, Liberty's on-site team worked closely with the vocational staff at BSDC to create and expand more off-campus work opportunities, including:

- Worked directly with vocational staff to re-orient their focus onto off-campus community-based employment.
- Provided training and modeling in employer development to the Community Liaison.

- Began networking with and visiting community employers and worksites in the Beatrice area and development of an employer database.
- Worked with BSDC vocational staff and Team Leaders to increase referrals for community-based Vocational Services.
- Directly assisted several individuals in taking advantage of newly identified employment prospects in the community.
- Provided training in the area of assessment to HSTS and Team Leaders that emphasized individual preference.
- Began “Job Club” curriculum to promote awareness of the importance of employment in people’s lives and increase opportunities both on and off campus.

Continuing improvements— Reorganization of management systems to integrate active treatment into IDT: As part of the on-going plan at BSDC, Liberty’s on-site staff implemented a number of initiatives to reorganize the facility management system to fully integrate active treatment into an effective interdisciplinary team process, including:

- Redesigned the Individual Program Plan document using best practices in the IDD arena.
- Mentored professional staff on writing training objectives that are measurable, functional and specific.
- Separated combined QMRP/Home Manager functions, designating which staff will function as QMRPs or as Home Managers.
- Clarified in-home supervisory structure on second and third shifts.
- Expanded available professional hours on weekdays and weekends to increase active treatment opportunities.
- Strengthened the Administrator-on-duty system with clearly defined duties.
- Developed and implementing a “team building” curriculum to improve cooperation and coordination.
- Established criteria for each professional discipline to prioritize individuals in most need of active treatment.
- Implemented systems of professional staff responsibility regarding client assessment, active treatment program development, program fidelity monitoring and direct care staff monitoring and training.
- Explored ways to move professionals’ offices closer to the client living areas for greater involvement and responsiveness.
- Changed role of HSTS from program developer of all active treatment to that of program assessment, development, monitoring and training in activities of daily living and money management skills as required by the federal regulations.

Improving Individual Support Plan process: Liberty's on-site specialists helped the BSDC staff to improve the overall process of developing, implementing and monitoring ISPs, which will promote more effective active treatment. They closely examined and revised ISP procedures. They helped develop quality indicators and a monitoring tool for the Neighborhood Administrator staff to evaluate IPPs, vocational, and speech and language services. They trained and mentored QMRP staff in more effective ISP methods.

Long term recommendations: Long term recommendations for Active Treatment for BSDC are contained in Liberty's Management Plan.

E. Healthcare and Therapy Services

The CMS Condition of Participation called "Healthcare and Therapy Services" refers to the full array of somatic health services, including medicine, nursing, pharmacy, physical therapy, occupational therapy, and speech/language audiology services. Liberty's accomplishments and recommendations for future improvement are presented below in three main domains of medical, nursing and habilitative therapies (PT, OT, SLP).

Improvement plan for medical services: Liberty brought in a physician specialist in intellectual and developmental disabilities to complete a detailed evaluation of strengths and deficiencies in medical care at BSDC and make practical recommendations for improvement to achieve compliance with CMS and DOJ standards. In particular, federal authorities have cited BSDC for failing to provide adequate preventive health care by identifying, assessing, treating and monitoring high risk residents and for inadequate collaboration and coordination among the various health care disciplines. One fundamental problem is the need for more physician time. At the present time, BSDC has only 1.5 physicians to serve 300 residents. The following recommendations have been made, but some will require additional on-site physician time to be adequately achieved.

Medical practice and protocols:

- Develop and implement a formal oversight mechanism to demonstrate compliance with the medical clinical practice guidelines.
- Increase the frequency of in-living-unit physician examinations of resident injuries, accidents and changes in condition.
- Institute proactive preventive screening protocols for adults with mental retardation from the National Guidelines Clearing House with particular regard to osteoporosis and cancer screening.
- Develop and implement protocols for risk identification, risk management, incident reporting and follow up of incidents, accidents, and injuries with appropriate oversight provided to aid compliance.

- Institute protocols for proactive identification and treatment of individuals with osteoporosis. Routine BMD testing and monitoring of vitamin D levels should be part of this effort.
- Develop and implement a protocol for medication augmentation of chemical restraint to proactively decrease the high incidence of potentially dangerous physical/mechanical restraint practices.
- Obtain Antibigram from the laboratory to assist with improved infection control.
- Identify individuals with prolonged QTc in a central data base with coordination by pharmacy.

Improve coordination among the health care team:

- Develop a protocol for integration of recommendations from the separate clinics that oversee seizures, diabetes, tardive dyskinesia, mental illness and other issues in order to avoid fragmented care and maintain clarity of primary responsibility.
- Develop a multidisciplinary team approach to fracture prevention to improve the potential to reduce fracture rates by utilizing evidence-based information from the American Medical Directors Association (AMDA).
- Develop guidelines for Neurology consultations to include the review of anti-seizure medications prescribed by a psychiatrist.
- Improve system for identification and reporting of adverse drug reactions in coordination with pharmacy, including increased participation in federal Medwatch program.
- Revise Psychoactive Medication Review protocol to include Pharmacy staff participation.
- Improve use/coordination of estimated creatinine clearance data with the pharmacy to guide reduced dosing for diminished kidney function.

Improve medical documentation procedures:

- Develop and implement a single medical/healthcare record to improve the system of charting and documentation and improve communication and care.
- Train physicians and nurses to improve the quality of documentation and develop a mechanism for oversight and review of records.
- Develop standards for documentation of physical examinations and other pertinent findings in progress notes.
- Establish standards for practitioner signatures on labs, X-rays, reports, etc.
- Develop physician practice protocols for charting the full complement of laboratory results pertinent to monitoring for various conditions and syndromes and for charting the synthesis of lab results with appropriate medical intervention.

- Develop verification documentation for Informed Consent for Psychoactive Medication in the health record.
- Refine the protocol for Psychoactive medication reviews to include documentation regarding definition of target symptoms and relevant data.

Improvement plan for nursing services: Liberty brought in a nurse specialist in intellectual and developmental disabilities to complete a detailed evaluation of strengths and deficiencies in nursing care at BSDC and make practical recommendations for improvement to achieve compliance with CMS and DOJ standards. The following recommendations have been made, but some will require additional on-site nursing to be adequately achieved.

Nursing practice and protocols:

- Increase the frequency of nursing examinations of resident injuries, accidents and emergencies such as prolonged seizures.
- Increase frequency of routine nursing observations to a daily routine to improve detection of signs and symptoms and changes in chronic conditions and increase opportunities to provide education and training to the residents, direct care and other staff.
- Increase the number of nurses who administer medications in the resident living areas to decrease the medication error rate and improve monitoring of the safe delivery of medication by the medication aides.
- Implement a formal pain assessment procedure as part of the routine nursing evaluation.
- Include Nursing as part of the Pharmacy and Therapeutics Committee reviews of trends and patterns in medication errors.
- Re-evaluate the distribution of nurses across the campus.

TRAINING:

- Provide training to all nursing staff regarding assessment of accidents and injuries.
- Provide training for nursing staff and medication aides on accurate documentation to prevent medication errors.
- Provide training to nursing staff effective communication with physicians regarding changes in resident conditions.

Documentation:

- Streamline and consolidate the record keeping system to improve communication, collaboration and consistency among health care professionals and direct care staff and to improve resident care and follow-up care.

- Improve individual specificity in nursing care plans and protocols for urgent/emergent changes in client health conditions.

Accomplishments and improvement plan for habilitative therapies: Liberty has accomplished the following activities and developed recommendations for future improvement.

Accomplishments:

- Completed all OT/PT Positioning Assessments, Positioning Plans, and IPP Addenda to support Positioning Monitoring system.
- Introduced Positioning Plans and Positioning Monitoring system to the IDTs and all staff to facilitate compliance with CMS Plan of Correction.
- Created a plan with a timeline for increasing opportunities for alternative positioning in active treatment areas.
- Completed Living Unit Environmental Assessments for four BSDC units along with recommendations to the Team Leader.
- Completed Speech/Language Audiology Services (SLAS) evaluations for four clients.
- Completed SLAS Adaptive Equipment Monitoring on all clients with adaptive equipment issued by SLAS.
- Streamlined and consolidated the record keeping system to improve communication, collaboration and consistency among health care professionals and direct care staff to improve resident care and follow-up care.

Recommendations in process:

- Expand Positioning Plans and Monitoring to a Physical/Nutritional Management system.
- Coordinate efforts of Developmental Therapy, Speech Therapy and Staff Development for individual-specific training issues.
- Establish training opportunities to increase staff awareness of both general and individual-specific positioning issues.
- Increase frequency of basic and specialized Positioning Training for all staff.
- Improve the referrals/requests procedures for Therapy Services (PT, OT, SLAS).
- Improve the Nursing Positioning Record (NPR) process, including how/how much staff are in-serviced, documentation, and data recording system.
- Establish a Quality Improvement system pertaining to Therapy Services/Positioning.

F. Quality Improvement

The importance of QI: Although “Quality Improvement” is not a CMS Condition of Participation, it will play a major role in the transformation and revitalization of BSDC because QI is the primary mechanism for measuring and monitoring the quality and effectiveness of services and for reducing risk through prevention and elimination of errors, injuries, accidents, abuse and adverse events. Ultimately, the QI Plan is a safeguard for the people at BSDC, ensuring that they are healthy and safe; have meaningful days and fulfilling lives; express their independence and individualism; have their human and legal rights honored, and live and work in a respectful environment.

QI Plan that is proactive, not reactive: Spearheaded by Liberty’s on-site QI team, a new and comprehensive QI Plan was created at BSDC and includes development of critical methodologies, systems and data collection that were not previously in place. The QI Plan is a data-driven tracking program that will encompass multiple performance indicators and measures. Reliable data will be collected at regular intervals on specified “routine” measures, but the QI Plan also allows for rapid early response to negative trends and any urgent or emergent issue at the earliest point of intervention. The QI Plan will enable the leadership team to evaluate the quality of services and to take action as the data indicate the need. Members of the *Quality Improvement Committee* include people served and staff from each clinical department.

Keeping people healthy and safe: While it is not possible to guarantee that no one will fall ill or have an unforeseen accident, it is possible to identify risk areas and to take steps to minimize each person’s likelihood of injury or incident. Abuse, neglect, or mistreatment of anyone who lives at BSDC is unacceptable. Liberty believes that a systems approach to address staff training and resources and monitoring of key risk areas will create a positive environment for both staff and people who live and work at BSDC. Additionally, other systems to track trends of injuries and incidents and to take swift action will abate any growing concern before it becomes a problem that affects people’s health and safety.

Key changes recommended and implemented: Under the guidance of Liberty’s on-site specialists, a comprehensive and integrated array of interventions and initiatives has been planned and activated. Many of the components have been implemented, while others will require additional resources from the State to be fully implemented. They are organized into several domains:

Emergency systems and preparedness: Liberty has developed a plan to conduct Behavior Drills, Emergency Drills and Medical Emergency Drills to make certain each person’s risks have been identified for response and to enhance each staff person’s knowledge regarding how to take immediate and appropriate action.

Training initiatives: Liberty recommends that all staff receive regular training in general

key safety areas (e.g., CPR, Heimlich, seizure precautions, etc.) as well as the specific needs of each person. Competency-based training modules, including use of in vivo training procedures, also need to be expanded and strengthened and the mastery of skills should be verified/reinforced with follow-up evaluation and training.

Prioritize recruiting: There is an urgent need for effective recruiting to improve staffing – both professional clinical specialists and direct care personnel – to carry out the outcomes identified by each person in his/her ISP.

Introduce and enhance multiple risk reduction mechanisms:

- Conduct comprehensive risk assessments for each individual that encompass both medical and behavioral risks.
- Evaluate each incident of restraint to evaluate if it was appropriate and if the person remains safe and if the current Behavior Support Plan and resources are adequate to prevent/reduce the likelihood of recurrence.
- Mandate regular reviews of the adequacy of any Behavior Support plan that uses any restrictive components. Any BSP that does not include a written Behavior Drill or a comprehensive functional analysis should be disapproved.
- Review each death to identify any issues, with increased attention to medical or nursing care, and make recommendations.
- Thoroughly investigate every allegation of abuse, neglect and mistreatment, suspicious injuries and injuries of unknown origin and take immediate action to protect people from further harm and track and act on trends. Implement a system of injury and allegation data collection and analysis.
- Monitor key risk areas with adequate numbers of well-trained medical professionals and QMRPs, including people with feeding protocols, frequent seizures, frequent episodes of aspiration pneumonia, need for physical transfer assistance, self-injurious behavior, aggressive, and other risk areas.
- Develop and deploy independent dedicated monitors to regularly evaluate people's health and safety in first-hand, direct fashion.
- Analyze whether ISPs are based on outcomes defined by the person and designed to practically achieve the desired outcomes.
- Empower various standing Committees to make vital decisions regarding safety and risk reduction with urgency and authority.
- Improve the quality, reliability, usefulness and timeliness of the performance data (e.g., injury reporting, medication errors, abuse, etc.) to facilitate prompt decision making and risk reduction responses.

Protecting and exercising client rights: People with disabilities are entitled to the same rights as any citizen. They should be aware of their rights and actively supported to exercise those rights that are important to them. The Liberty team has identified the need for protecting client's rights at BSDC to meet federal standards and contemporary practice, including:

- Expand the role of the Human Rights Committee to go beyond reviewing post-event restrictive Behavior Support Plans to evaluating the need for the proposed rights restriction and to include development of related policies and procedures, making site visits to places where people live and work, reviewing trends in the use of restrictive procedures, and re-examining all substantiated cases of abuse, neglect, or mistreatment.
- The Human Rights Committee should see that there are systems in place that support people to exercise their rights, including deployment of independent, dedicated monitors to regularly evaluate how people are exercising their rights.
- Staff need to be specifically trained to understand the importance of client's rights, generally, and to know and support the rights that are priorities for the individuals they support, specifically.
- Each person should have an individual rights assessment that is conducted in a face-to-face manner with the client him/herself and the staff and persons who best know the client.
- Achieve a fundamental transformation of philosophy and values to bring BSDC in compliance with contemporary standards of care and federal requirements.

G. Right-Sizing and Community Transitioning

Achieving an ambitious goal: Although "right-sizing and community transitioning" is not a CMS Condition of Participation, it is an extremely important issue for Beatrice State Developmental Center and an action upon which full compliance may depend. It is not only a compliance priority, but a priority for consumer advocate groups and the U.S. Department of Justice. The State of Nebraska has publicly asserted its goal to transition over 100 of the current residents into the community by the end of 2008. The complexity of achieving community placements for so many individuals in such a short period of time is a commendable goal, but it will require strong, well-coordinated efforts and sophisticated methods to be successful. It is important to remember that many of the individuals at BSDC have complex medical needs involving multiple medical conditions and atypical combinations of multiple medications that exceed the capacities of traditional community health providers. Other individuals have complex and challenging behavioral issues that also exceed the skills and training of typical residential providers.

Transition entails a combination of detailed planning and preparation for each individual resident; proactive education, consultation and support for community providers; supporting transitions; risk management/outreach systems for monitoring safe transitions; incentives to encourage community providers to take individuals with more intensive and special needs; individual quality monitoring following placement and much more.

National trends toward more cost-effective, community-based services: The field of developmental disabilities has dramatically changed in the last two decades. Current thinking, as well as human science, has consistently shown that most people with developmental disabilities are best supported when living in small, individualized settings like those where people without disabilities live. This is reinforced by the Supreme Court's Olmstead decision. There is a clear national trend of closing institutions and migrating facility-based services to the community, which has resulted in measurable savings while improving the lives of the people who are supported. BSDC is impacted by this national trend and cost containment strategies. This will necessitate increasing focus on community placement and building provider capacity in the community.

New leadership position to direct placements: Liberty strongly advises the creation of a new leadership position at BSDC that will prove increasingly important in the coming months and years: **Director of Community Placements**. In the long term, BSDC should have this position to focus exclusively on advocating and facilitating movement of as many residents as possible wishing to move into the community. This would entail oversight of community placement planning and initiatives; working with families, Medicaid case managers, advocates, and community providers; and helping to build community provider capacity through provider recruiting, funding initiatives, and resource development. This individual will also be responsible for developing plans for right-sizing the facility, implementation of community placement staff and initiatives, and plans to facilitate placements of residents in community settings.

Centralized team to bridge facility to community: Based on our experience with other states, Liberty would also recommend the development of an on-site team of placement specialists at BSDC who will manage the person-centered planning and placement process for each individual resident. By applying a more thoughtful, but aggressive approach to building supports in the community, clients at BSDC can be safely transitioned to appropriate, less restrictive settings. At the same time, this will enhance the quality of life for these consumers by successfully integrating them into their communities with a greater degree of independence, dignity, choice and safety. These placement specialist roles could easily be assumed by present state staff in social worker roles.

The role of the IDTs in discharge and placement: The Inter-Disciplinary Teams (IDT) at BSDC should be responsible for ensuring that residents are receiving an appropriate level of care in the most integrated setting possible. The IDT should be more active in assessing the person and making recommendations for community living settings when appropriate.

The IDT should be expected to refer individuals to alternative service settings when they are in need of services other than the primary Active Treatment services provided in an ICF/MR setting (e.g., referral to a skilled nursing facility if the person has intensive medical needs that prevent him/her from benefiting or participating in active treatment). The IDT is also responsible for discharge planning on an ongoing basis. This is different from the actual discharge process. Discharge planning includes the identification of barriers that might prevent the individual from living in a community setting and the identification of programmatic interventions that teach skills to overcome those barriers or other interventions to provide supports to the person while they are learning new skills.

The role of the transition specialists: The transition specialists work closely with the IDT in preparing and planning placement. The transition specialist is the primary liaison between BSDC, DDD Service Coordination, DD and other service providers, and parents/guardians throughout the process. The expressed recommendations of the IDT should be inclusive of the parent/guardian's decision. Thus the IDT should include the parents or guardian and see that explanations regarding discharge planning and level of care are carefully explained and consent is obtained. The key is to see that the identified community-based resources can fully meet the person's needs, that the person desires to move, and that the parents/guardians agree and support the placement plan.

Facilitating placements in collaboration with community partners: The proposed placement specialists should work closely with community providers and agencies to facilitate the expansion of community supports and services, which will support long-term security, stabilization, and satisfaction. It is the relationship between institutions and the provider community that can create delays or failure of placement of individuals from institutions into community settings. Placement specialists should meet directly with providers, make sure that they are familiar with the resident, have established a relationship prior to discharge, and are actively involved in the development of the placement plan.

Support and education: One of the greatest obstacles to successful placements can be the low expectations about the abilities of a resident to live outside the institution. Many individuals can thrive in their new living arrangements if they and their families and support network are given the appropriate specialized supports. Placement Specialists should educate staff and families about potential and probable positive outcomes and, more importantly, identify and assess the availability of the kind of supports that clients and providers need to succeed in less restrictive community settings.

Extending facility expertise with challenging behavior directly into the community: BSDC should extend its facility-based expertise directly into the community. Placement teams should provide pre-training to community staff in new methods of positive behavioral supports. Every transition plan should expect the proposed community provider to travel to BSDC and meet with the resident and involved staff at the facility. This is an opportunity to provide direct guidance and training specific to the individual client. Similarly, the

placement staff should actually travel with the client to the proposed new home in the community in order to meet new providers and supports, assess the environment and determine if any additional supports are needed. Placement teams should conduct regular routine follow-up contacts with the client and his/her supports in the community. Placement teams should continue to be available to community providers and staff for expert consultation on any problems that may arise, such as complex medical, pharmacological or behavioral issues. Many community providers lack experience with more challenging issues and need access to skilled professionals that have the technology to handle these concerns effectively.

Future changes: In the future, as more individuals transition into the community, BSDC will serve individuals whose needs are more difficult to meet in integrated community service settings. The individuals served at BSDC will increasingly have more intensive, and complex needs, requiring a combination of enhanced behavioral and/or medical services. Assessments to identify barriers to living in a more integrated community setting through the DHHS Division of Developmental Disabilities should begin at the time of admission. Discharge planning should be reevaluated at least annually at the individual's Individual Program Plan (IPP) meetings. As the individuals' physical and medical needs change, discharge planning should also include referral to other, more appropriate, types of services (e.g., nursing facility, assisted living, and hospice).

4. Recommendations for Staff Positions

A. Deputy CEO – Active Treatment Services

The Deputy CEO for Active Treatment has a number of crucial responsibilities and challenges to manage. First, s/he needs to continue to work diligently to establish an interdisciplinary team focus at BSDC. This has required major changes to the pre-existing system in which each clinical discipline operated independently of the others, which resulted in care that has been fragmented, disorganized and does not fully meet the needs of individuals. Second, s/he should continue to re-engineer the clinical assessment procedures at BSDC so that it is entirely in the hands of clinical professionals on the interdisciplinary teams who will develop the active treatment plans. The management structure has been reorganized so that all of the clinical disciplines that deliver active treatment report to the CEO of Active Treatment, thereby enabling him/her to systematically mold the interdisciplinary teams into more effective functions. That entails multiple initiatives, such as changing job descriptions, clarifying disciplinary assessment responsibilities, developing protocols for integrative assessments, and actively engaging the clinical staff with the direct care staff in the delivery of active treatment. This enables the direct care staff to benefit from training and direction from the clinical professionals. It also enables the residents to benefit from improved active treatment programming that is integrated by professionals and supported by regular clinical assessment as required by Title XIX.

B. Deputy CEO – Quality Improvement

The Deputy CEO for Quality Improvement has a number of crucial responsibilities and challenges to manage. S/he is responsible for all aspects of developing and managing an on-going QI program, including selection of measures and indicators; development of the mechanisms to gather reliable timely data; mechanisms to analyze the incoming data for identification of trends; recommendations to address emergent issues; systems to monitor implementation of recommendations; and mechanisms for evaluating the effectiveness of the interventions. The Deputy CEO for QI also has the vital role of communicating the philosophy of continuous quality improvement and the importance of educating and involving staff from all departments and all function in the total QI process.

C. Deputy CEO – Neighborhood Services

The Deputy CEO for Neighborhood Services is responsible for ensuring appropriate and adequate staffing for all residential functions from day to day as well as future planning and reorganization to achieve a more effective consolidation of housing units at BSDC. Thus, this leadership professional manages workforce deployment and scheduling and monitors direct care staff and supervisory staff patterns in the current living units. This includes managing the deployment of the direct care staff for one-to-one supervision and intensive interventions as needed. At the same time, the Deputy CEO for Neighborhood Services should also work with BSDC staff in planning and determining the number of homes that can be safely staffed with existing resources as the facility consolidates into fewer housing units. This position plays a major role in promoting coordination between direct care personnel and the clinical staff in implementation and monitoring of active treatment and ISPs. The position should continue to develop appropriate senior supervision on the second and third shifts and weekend/holidays, including on-call emergency response capability.

D. Psychology Director

BSDC should procure the services of a well qualified, experienced psychologist to direct the provision of psychology and behavioral services at BSDC. The Director should be a doctoral level psychologist and should have specialized training and experience in working with people with intellectual and developmental disabilities who exhibit challenging behaviors, including self-injurious behavior, aggression, inappropriate sexual behavior, pica, fire-setting, verbal and/or behavioral outbursts, and other issues. S/he should understand the role of the environment in evaluating the context for people's challenging behaviors and have expertise in the use of positive approaches to address challenging behaviors safely, effectively, and humanely. S/he should understand the role of the environment in evaluating the needs and support context for people's challenging behaviors. Given the lack of behavior analysis services at BSDC, the new Director of Psychology would have an important role in expanding and building this crucial program capacity. Through a combination of supervision, training and new staff, BSDC

should establish a staff of well qualified Behavior Support professionals with the skills to help people with challenging behaviors.

E. QMRP Director

The role of QMRP Director is absolutely crucial because BSDC's provision of active treatment has been cited by federal authorities for its lack of coordination and collaboration between and among the various clinical disciplines and the residential staff. In its careful assessments of the situation at BSDC, Liberty's on-site experts worked diligently to introduce new organization and reorganize existing processes and structures to (1) integrate the various clinical disciplines into collaborative teams, (2) engage the clinical staff with the residential direct care staff to generate collaborative action, (3) increase engagement of clinical staff with the residents; (4) establish standardized procedures for key functions, especially the development and implementation of ISPs; and (5) restore the clinical specialists in the role of developing active treatment programming. BSDC should establish a highly qualified, experienced professional who can spearhead the new training, methods, and philosophy needed to accomplish these multiple complex initiatives.

F. Vocational Director

There has been a major shift in philosophy and approach in the field of developmental disabilities with regard to vocational services. The so-called "sheltered workshop" concept has been faulted for having segregated people from real world work experiences and giving them mindless, boring, and unproductive tasks to perform. The current person-centered approach holds that people can learn real vocational skills and perform many meaningful jobs in the community. The best job training should take place in an actual work setting using the skills of a job coach. Prior to Liberty's involvement, BSDC had no job coaches and offered few real world employment opportunities.

To facilitate the ultimate goal of greater self-sufficiency in the community, BSDC should procure an IDD-experienced Vocational Director to work closely with the vocational staff to re-orient their focus onto off-campus community-based employment, promote awareness of the importance of employment in people's lives, increase opportunities both on and off campus, increase referrals for community-based Vocational Services, and create and expand off-campus work opportunities with local employers.

G. Recommended Positions to be Filled

Given the rural location of BSDC and the unique challenges of the population served, the State has had a long-standing struggle to recruit and retain staff at BSDC. There are a large number of positions that are currently vacant and need to be filled, including administrative, clinical and direct care personnel. In addition to the existing vacancies, Liberty recommends the addition of some new leadership and clinical positions, which are highlighted in blue and described in the narrative following the chart.

POSITION	FTEs
LEADERSHIP	
Director of Transition and Transformation	1.0
Director of Community Placement	1.0
In-Service Director	1.0
Assistant Director of Psychology	1.0
CLINICAL PROFESSIONALS	
Psychiatrist	1.0
Behavior Analyst	5.0
Speech Therapist/Dysphagia	1.0
Speech Therapist/Communication	1.0
Occupational Therapist/Dysphagia	2.0
Physical Therapist	2.0
Neurology Consultant	0.2
Nursing Staff	
LPN (2nd Shift)	7.0
LPN (3rd Shift)	3.0
Staff Nurse (2nd Shift)	7.0
Staff Nurse (3rd Shift)	3.0
Physician	1.0
Direct Support Professionals (2 nd Shift)	30.0
Direct Support Professionals (3 rd Shift)	30.0

H. Other Leadership and Clinical Positions Needed at BSDC

Liberty believes that two new leadership positions and a significant number of clinical professionals are needed to accomplish the DHHS Five Point Plan and establish long-term regulatory compliance at BSDC. The leadership positions are described first.

1. Director of Transition and Transformation

This recommended position would establish a direct linkage between Director of the Division of Developmental Disabilities and execution of the Five Point Plan and regulatory compliance at BSDC. The position would assure that transformation efforts have a “quarterback.” The position would function as the primary catalyst for achieving CMS compliance and the commitments of the DHHS Five Point Plan. A highly qualified senior director should bring immediate on-site experience with DOJ, CMS compliance, CMS recertification, litigation, right-sizing and community transitioning into direct play at BSDC and with other DHHS systems.

2. Director of Community Placements

Given the State's desire to transition over 100 residents at BSDC to the community, Liberty strongly recommends the addition of a Director of Community Placements and a staff of at least six Transition Specialists/Social Workers. The Director of Community Placements would report directly to the Deputy CEO of Active Treatment. The reason is that federal and state regulations require that all individuals residing in an ICF/MR should participate in a continuous active treatment program which includes training and services to teach skills to address barriers to living in a less restrictive environment (i.e., integrated community service setting). To start the placement process, the interdisciplinary team should complete a detailed assessment of each individual to determine what supports (e.g., active treatment) will be required in the community to support his/her long-term success. The supports are entirely individualized and frequently entail arrangements for residential care, medical care, behavioral services, employment, and other supports. The placement process then entails finding and matching community providers who can meet the individual's needs. The community placement staff would facilitate site visits by staff and clients prior to placement to develop an appropriate plan. Although the Department of Children and Families will facilitate the transition, it is important that BSDC staff remain involved and available for on-going consultation and guidance regarding the individual's support plan and needs as well as to provide training to the staff and providers that may be receiving the individual client. The Director of Community Placement would also have an important community relations function, helping parents and guardians to understand the advantages of community placement over institutional care and gaining their cooperation and trust in completing the placement.

3. Psychiatrist

At the present time, BSDC has limited access to a part-time psychiatrist. Liberty strongly recommends a full-time psychiatrist who has significant experience working with individuals with intellectual and developmental disabilities. The need for psychiatric services is a deficiency identified by both CMS and the DOJ. The expansion of on-site psychiatry time will be able to address a number of risk management issues that have been identified at BSDC including the following:

- Strengthen the coordination and communication between the psychology/behavior analysis staff and the psychiatrist to eliminate the inappropriate use of psychiatric medications.
- Enable the frequency of attention needed to conduct more proactive monitoring of clinical status vis a vis medications by the interdisciplinary team so that adjustments to psychiatric medication can be made promptly and effectively.
- Establish clear rationales for medication regimens that match diagnosis.

- Improve prescribing practices by reducing excessive use of first-generation anti-psychotic medications, benzodiazepines, and anticholinergic medications by requiring clinical justification and more intensive scrutiny, which will avert inappropriate exposure to tardive dyskinesia, Parkinsonism, psychological dependence, loss of behavioral inhibition, and other side effects.

4. Behavior Analysts

Unfortunately, it has been common practice at BSDC to use very restrictive interventions, such as 4-point mechanical restraint, to manage behavior. This is a source of significant risk and increasing actuality of injury to BSDC residents and staff. Likewise, there has been excessive and inappropriate use of psychiatric medications to control behavioral issues, which is another major risk exposure. Moreover, the rate of one-to-one observation, with its severe demands on the available workforce, has been unnecessarily high. All three of these high risk practices can be dramatically reduced, and virtually eliminated, through the introduction of contemporary person-centered methods of positive behavioral supports based on functional behavioral analysis. This is a serious weakness at BSDC which will require the introduction of several behavior analysts. Although the facility has a sizeable number of psychologists, there is a lack of familiarity and training in contemporary methods of applied behavior analysis that focus on environmental and contextual factors.

Behavior analysts are regarded as absolutely essential core members of a contemporary ICF/MR facility and will be crucial in achieving a successful turn-around. BSDC has none. We believe this is the basis for multiple deficiencies identified by federal authorities, including:

- Failure to provide adequate and appropriate behavior programs due to inadequate observational analyses.
- Infrequent updates related to changes in residents' behaviors throughout the year.
- Inadequate implementation of behavioral plans, which places residents at risk of continued injury and harm through continued exposure to restrictive intervention procedures and continued institutionalization.
- Lack of training for direct care staff in use of positive behavioral supports and implementation of active treatment plans.
- Need to include behavior analyst representation in the Incident Review process to enable IDTs to develop preventive programs for individual residents based on their incident/injury experience.

5. Habilitative Therapists

- a. Speech Therapist/Dysphagia**
- b. Speech Therapist/Communication**
- c. Occupational Therapist/Dysphagia**
- d. Physical Therapist**

The next four positions are collectively known as habilitation therapies. In an effective interdisciplinary team, the assessments and interventions of these disciplines are highly interrelated. The federal authorities have targeted this group of therapeutic services for multiple deficiencies at BSDC. Clearly, the chronic staffing shortages in these four vital positions is a leading cause of noncompliance. Given the lack of staff, the habilitative therapists cannot be fully proactive in anticipating and identifying problems at the earliest point of intervention. They cannot conduct regular evaluations in the frequency needed to identify problems quickly and monitor conditions adequately. Instead, they only become involved with clients when a problem arises, eliminating the possibility of developing and implementing preventive plans and supports.

Liberty strongly recommends increasing the numbers of filled positions so that they can personally examine individuals to detect signs and symptoms of illness, deformity, and develop and implement corrective measures to reduce/eliminate preventable risks to residents. Specifically residents at BSDC do not receive adequate nutritional or physical supports at BSDC to prevent risks due to swallowing disorders, digestion problems, misalignment, skin breakdown, aspiration pneumonia, gastrointestinal problems, contractures/deformity and decubitus ulcers.

Federal authorities have also cited BSDC for its failure to develop effective safeguards to reduce the frequency of resident falls, which places residents at great risk of harm and serious injury, including fractures and serious lacerations. A pattern has been identified at BSDC in which numerous residents have suffered multiple falls, but they were not identified as individuals at-risk for falling. As a result, BSDC failed to provide adequate preventive interventions. This is one of primary roles of the Occupational Therapists and Physical Therapists and again points to the urgent need for adequate numbers of these professionals.

6. Neurology Consultant

At the present time, BSDC has access to a neurologist for only one half day per month. Liberty strongly recommends a major increase in on-site neurology consultation, particularly with regard to improved seizure control, an area of high risk exposure. By increasing the number of neurologist consultations, it will be possible to closely monitor individuals who are currently beset by very frequent, poorly-controlled seizures. Given the risk of negative interactions between psychiatric medications and anti-convulsive agents, the increase in neurologist time will also enable the neurologist and psychiatrist to effectively coordinate medical care and medications for improved effectiveness and safety.

7. LPNs and RNs

The shortage of nurses at BSDC has not allowed the nursing staff to administer medications to residents nor to observe and evaluate each resident on a regular basis. There are serious shortages of nurses at BSDC. This has resulted in deficiencies in providing preventive health care and diminished collaboration and coordination between and among the various health care disciplines. For example, BSDC has been criticized for failing to adequately identify residents who are at risk of harm from aspiration/choking, bowel impactions, decubitus ulcers (bedsores) and other conditions. By increasing the number of nurses, it will be possible to be more proactive and preventive by identifying, assessing, treating and monitoring high risk residents. It will also help to reduce the frequency of medication errors, which can place residents at risk of harm. Increased nursing will enable nurses to spend much more direct clinical time with the residents and apply their technical experience more frequently. They will be able to assess individual signs and symptoms of illness and/or changes in condition and provide appropriate treatment at the earliest point of detection. They will be able to provide adequate preventive health care by identifying, assessing, treating and monitoring high risk residents.

8. Physician

At the present time, there is only 1.5 FTE physicians to serve the approximately 300 residents of Beatrice State Developmental Center, which is not enough to provide adequate treatment and monitoring of medical health. In particular, the facility has been cited by federal authorities for deficiencies in providing preventive health care by identifying, assessing, treating and monitoring high risk residents and for poor collaboration and coordination between and among the various health care disciplines. These deficiencies can be eliminated by increasing the number of physician hours at BSDC. To date, physician shortages have made it difficult for physicians to spend enough time with other medical personnel, interdisciplinary staff, residential staff and even the clients themselves to gain a thorough understanding of the resident and his/her health status. It is especially helpful when physicians have the time to visit patients in their living areas and see them in

their daily routines to gain a holistic understanding of the person and his/her health issues. Increased physician time will also facilitate closer coordination and communication between the physicians and the nursing staff. Moreover, the increase of physician hours will facilitate the establishment of an array of preventive and health maintenance protocols. For example, Liberty's physician expert has recommended the following protocols at BSDC:

- Preventive screening protocols for cancer.
- Protocols for proactive identification and treatment of individuals with osteoporosis.
- Protocols for integration of recommendations from the separate clinics that oversee seizures, diabetes, tardive dyskinesia, mental illness and other issues.
- Protocol for medication augmentation of chemical restraint to proactively decrease the high incidence of potentially dangerous physical/mechanical restraint practices.
- Interdisciplinary approach to fracture prevention.
- Protocols for risk identification, risk management, incident reporting and follow up.
- Guidelines for Neurology consultations regarding anti-seizure medications prescribed by a psychiatrist.
- System for identification and reporting of adverse drug reactions.
- Protocol for Psychoactive medication reviews.

AN INDICTMENT OF INDIFFERENCE

**A Report of the Investigation of the Beatrice State Developmental Center
By Nebraska Advocacy Services, Inc.
*The Center for Disability Rights, Law and Advocacy***

December 5, 2007

AN INDICTMENT OF INDIFFERENCE

EXECUTIVE SUMMARY

The current, repeated inability of Nebraska state officials to protect and provide active treatment to the residents at the Beatrice State Developmental Center (BSDC) who are entrusted to their care did not materialize overnight. The problems and failures at the Beatrice State Developmental Center are systemic, chronic, and have persisted for years. Nebraska Advocacy Services, Inc. (NAS) has reviewed reports of surveys conducted by the United States Department of Health and Human Services Centers for Medicare and Medicaid Services (CMS). Our review of CMS survey reports since November 2001 documents the critical and substantial failures of state officials to meet accepted professional standards of care at BSDC. The failure of state officials at BSDC to meet these standards as cited in the October 2006 and April 2007 CMS survey reports are merely the most recent. It is not acceptable that these failures have been known and tolerated for years by state officials who have the responsibility to protect and habilitate the 350 residents at BSDC.

On October 2, 2006 CMS found that BSDC was not in substantial compliance with the applicable federal rules, regulations and interpretive guidelines of accepted professional standards of care in a substantial number of critical areas, and the conditions at the facility constituted an **immediate jeopardy to resident health and safety**. During the course of a follow up visit on April 19, 2007 CMS surveyors again found that BSDC was not in substantial compliance with the applicable federal rules, regulations and interpretive guidelines of accepted professional standards of care in seven out of eight critical areas, and the conditions at the facility constituted **immediate jeopardy to resident health and safety**. These findings by CMS meant that over \$28,000,000 in federal funds could have been withheld from the total BSDC budget of slightly more than \$50,000,000.

Upon notification of the serious and substantial finding by CMS of **immediate jeopardy** in October 2006 Nebraska Advocacy Services, Inc., *The Center for Disability Rights, Law, and Advocacy* (NAS) immediately contacted CMS, the ARC of Nebraska, and the Acting Administrator of BSDC for documentation of the CMS findings. NAS negotiated an Access Agreement with the State of Nebraska for access to the BSDC facility, its residents and staff, and to review the records of BSDC residents. Only by this complete access to the facility, residents, staff, and records at BSDC, could NAS fulfill its federal mandate and monitor the safety of those residents.

Subsequently, NAS legal advocacy staff visited all residential and programmatic units to question staff and observe the residents living there. NAS also requested information about the specific residents (and their guardians) referenced in the CMS reports. Since November 2006, NAS legal advocacy staff has reviewed hundreds of incident reports and visited BSDC twice each month to conduct inspections and on-site reviews. As this report documents, from March 2007 through September 2007, NAS monitoring has

identified a relentless series of incident reports of serious harm and ineffectiveness in response to the needs of BSDC residents.

We find that, as a matter of law, state officials have violated and continue to violate the constitutional and statutory rights of BSDC residents. The U.S. Supreme Court has recognized that persons with developmental disabilities who reside in state facilities (such as BSDC) have a protected liberty interest in safety, a right to minimally adequate training to provide for their safety and freedom from unreasonable restraints, and adequate levels of care according to accepted professional standards of care. Further, CMS regulations require facilities like BSDC to protect people in their care from harm, provide them adequate staffing, protect them from abuse, and to ensure “active treatment” to reduce dependence on drugs and physical restraints. The evidence is clear that Nebraska state officials failed and continue to fail to provide adequate active treatment/habilitation for residents at BSDC; rather, staff convenience necessitated by chronic understaffing drives habilitation.

NAS also concludes that chronic and persistent staff shortages are impacting the safety and habilitation needs of the residents. Direct care staff members are working massive amounts of overtime and double shifts. Inadequate numbers of minimally trained direct care staff plus a greater number of residents who require significant behavioral interventions have **created an environment in which harm and risk of harm have risen dramatically**. Further, departure from accepted professional standards of care to provide active treatment escalates the maladaptive behaviors of residents, thereby **creating a downward spiral of greater chaos and violence within BSDC**.

To alleviate and remedy the harmful and chaotic conditions as they currently exist for residents at BSDC, NAS recommends:

- Establishing within BSDC a culture of respect and valuing of all people.
- Modeling habilitation and behavior programs on principles of consistent, positive reinforcement.
- Conducting comprehensive evaluations and assessments for all residents of BSDC.
- Preparing a timeline to significantly reduce the current population by placement into appropriate community settings.
- Substantially increasing compensation for direct care and professional staff.
- Providing staff with adequate competency-based behavior management training.

- Creating an Oversight Commission by the Legislature to envision a unitary integrative system of habilitation services and supports.
- Creating a Section of Civil Rights Enforcement within the Department of Health and Human Services for the protection of the civil rights of individuals residing within all of Nebraska's residential facilities.

NAS firmly believes that any effort to change the failures documented in this report must be grounded in the principles of respect for human dignity, affirmation of each resident as a valued citizen, assurance of the bodily integrity of every resident, and a commitment to the protection of their legal and human rights. It is our fervent hope that this report will move the public to say, "Enough! Enough of this relentless cycle of chaos and violence! Enough promises!"

It is time for Nebraska state officials, in both the Executive and Legislative branches, to take the action necessary to ensure the protection and safety of our most vulnerable citizens. It is time to put an end to the indifference of state officials that has resulted in the unfettered growth of institutional deficiencies, failures to meet accepted professional standards of care, and injury and harm to the people living at the Beatrice State Developmental Center.

PREFACE

Nebraska Advocacy Services, Inc. (NAS) is federally mandated to provide legal and other advocacy services on behalf of persons with disabilities, including persons with developmental disabilities and persons with mental illness. NAS is authorized to investigate potential abuse or neglect impacting such persons and to monitor their health and safety in both institutional and community settings. NAS is also authorized to pursue legal, administrative and other remedies and approaches to ensure the protection of the rights of persons with disabilities.¹ NAS is appreciative of those state officials, BSDC administrators, professionals, and direct care staff who have assisted NAS in fulfilling its federally mandated authority and responsibility.

We dedicate this report to all past, present and future residents of the Beatrice State Developmental Center (BSDC) and especially to the memory of Ms. Kristine Everitt (1946-1999). Both the historical record and recent federal surveys of BSDC evidence a long-term pattern and practice of failure on the part of Nebraska state officials responsible for the protection and treatment of people living at BSDC to acknowledge their humanity and respect their dignity and privacy. Their stories shall not be forgotten. It is our fervent hope that this report will not only serve to document their struggle to achieve full equality and liberty, but will also create an opportunity for the critical dialogue that is needed to address this deplorable situation.

¹ These authorities are conferred under federal statutes, including the Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 (“the DD Act”) U.S.C. § 15001 *et seq.* and its implementing regulations at 45 C.F.R. Parts 1385 and 1386; the Protection and Advocacy for Individuals with Mental Illness Act (“the PAIMI Act”), 42 U.S.C. § 10801 *et seq.*, and its implementing regulations at 42 C.F.R. Part 51; and the Protection and Advocacy for Individual Rights Act (“the PAIR Act”), 29 U.S.C. § 794e and its implementing regulations at 34 C.F.R. Part 381. These statutes will be referred to collectively as “the P&A Acts.”

HISTORICAL ORIGINS OF THE BEATRICE STATE DEVELOPMENTAL CENTER

In 1885, the Nebraska legislature established the Nebraska Institution for Feeble-minded Youth (NIFMY) to be located at Beatrice, Nebraska.² The legislature appropriated an initial \$100,000.00 and the City of Beatrice donated 40 acres of land for the site of the institution.³ The purpose of the Nebraska facility was clearly set forth in the initial legislation of 1885:

Besides shelter and protection, the prime object of said institution shall be to provide **special means of improvement** for that unfortunate portion of the community who were born or by disease have become imbecile or feeble-minded, and by a **wise and well adapted course of instruction** reclaim them from their helpless condition, and through the **development of their intellectual** faculties, fit them as far as possible for usefulness in society. To this end there shall be furnished them such agricultural and mechanical education as they may be capable of receiving.⁴ (Emphasis supplied)

The Nebraska Act in 1885 mirrored the national focus from external, community productivity to an internal custodial function for education.⁵ The first three children arrived in 1887 and by the end of the year, 65 children were living at the institution.

² Act of March 5, 1885, ch. 52, 1885 Neb. Laws.

³ Id. The legislative enactment in 1885 established the funding mechanism to be an “annual tax levy on the taxable property of the state, not to exceed one-eighth (1/8) of one million the dollar.” The Nebraska Institution for Feeble-minded Youth at Beatrice conceptually rested on the educational ideology of Edouard Séguin of the Parisian institution, Bicêtre, but which had been significantly modified and popularized in America in 1847 by Samuel Gridley Howe in Massachusetts. In Séguin’s ideology, “idiocy” was a failure of the will. Training techniques used by Séguin stressed excitation of the will, invigoration of the muscles, and controlling the senses which would lead to higher cognitive development. Proper education required physiological training to improve cognitive development. However, the American proselytizers, such as Howe, emphasized the pathological and degenerative properties of “idiocy.” These medical categories would quickly dominate and replace the educational underpinnings. This burgeoning conflict between an educational ideology and the medical pathological view was reflected in the founding legislation in 1885 for the Nebraska Institution for Feeble-minded Youth at Beatrice. See also Part II Physiological Education in Séguin, *Idiocy: and Its Treatment by the Physiological Method* (New York: William Wood & Co. 1866).

⁴ §2 Act of March 5, 1885, ch. 52, 1885 Neb. Laws; See also: Séguin, *Idiocy: and Its Treatment by the Physiological Method* supra. Within the very seminal legislative foundation creating the Nebraska Institution for Feeble-minded Youth at Beatrice in 1885 lurked the ascendant pathological medical premise that would stifle the educational ideology with all its promise of training and would become the very means of institutional perpetuation.

⁵ See generally: Trent Jr., *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley, California: University of California Press, 1995) 11-39; Rothman, *The Discovery of the Asylum: Social Order and Disorder in the New Republic* (Boston: Little Brown and Company, 1971) 109-154; Schalock, ed., *Out of the Darkness and into the Light: Nebraska’s Experience with Mental Retardation* (Washington, D.C.: American

The primary objective of the 1885 legislation creating the NIFMY was to establish a place where people could be sent to learn how to become productive citizens through education and training. The prevalent belief was that this could only occur in a school or setting segregated from family and community. Superintendents of facilities, such as the one at Beatrice, continued to use this assumption to justify expansion of the institutions. There were two primary justifications for the segregationist rationale. First, the *expertise justification* held that only special facilities could ease the burden of care of families and the community for their “feebleminded children”. Second, the *only alternative justification* held that if they were not institutionalized they would eventually end up in prison or the poorhouse.⁶ This fundamental and still fully unquestioned rationale, with its subsequently articulated dual justifications, continues to be rationale for the Beatrice State Developmental Center one hundred and twenty years later.

At the turn of the century, a brief twelve years after the first admissions, the seeds of the conflict between the educational ideology and the medical pathology view not only were firmly rooted into the institution at Beatrice, but had grown into a dual system of training “the educable” and segregating the “non teachable” in custodial confines.⁷ By 1914, the pathological custodial asylum model became dominant and remained so until the 1960s. People that were forced to live at the Beatrice facility had become in the eyes of the public and policy officials, both nationally and at the state level, “menaces” lacking moral restraint; “degenerates” spreading venereal disease, prostitution, illegitimacy,

Association on Mental Retardation, 2002) 103-122. Mason and Menolascino, [The Right to Treatment for Mentally Retarded Citizens: An Evolving Legal and Scientific Interface](#) 10 Creighton L. Rev. 124 (1976) 127-137.

⁶ Mason and Menolascino, [The Right to Treatment](#), supra at 130; see Wolfensberger (1976) The Origin and Nature of Our Institutional Models in R. Kugel and A. Shearer, eds., *Changing Patterns in Residential Services for the Mentally Retarded*, (Washington, D.C.: President’s Committee on Mental Retardation 1969) 150-179.

⁷ *Out of the Darkness*, supra at 11-113. The foundational philosophy of “moral treatment” and its requirement of humane, kind treatment with restraint sparingly used only to prevent immediate self harm or harm to others eroded as facilities like the Nebraska Institution for Feebleminded Youth at Beatrice transformed from schools to small institutions, and then to larger institutions emphasizing custodial confines.

pauperism, and other forms of social evil and social disease.⁸ Segregation and sterilization to protect society from “deviant” individuals with mental retardation became the *raison d’être* for the Beatrice facility.⁹

In 1915, in rapid succession, the Nebraska legislature enacted legislation designed to stop the spread of “the menace.” The year 1915 would be “the year of three strikes and you’re out” for individuals with mental retardation in Nebraska. First, a sterilization law was passed to prevent reproduction by individuals with mental retardation.¹⁰ Next, the legislature enacted the first civil commitment law including individuals with mental retardation.¹¹ Finally, the legislature mandated the Nebraska Institution for Feeble-minded Youth at Beatrice to accept people who were judicially determined to be “idiot, imbecile, or feeble-minded.”

The first sterilization occurred at Beatrice in 1917, and when the sterilizations ended in 1966, 752 persons at the Beatrice facility had been denied their fundamental human right to reproduce and had their right to their physical bodily integrity violated under the mandate of the Nebraska legislature and the authority of the Nebraska Supreme Court.¹² In 1921, the *de facto* segregative role of the Nebraska Institution for

⁸ Wolfensberger, *supra*. at 155; Mason and Menolascino, *supra* at 131 fnt. 17; Trent, *supra* 131-183.

⁹ Mason and Menolascino, *supra* at 133 fnts 21-23. See also *Out of the Darkness*, *supra* 117-119.

¹⁰ Act of April 8, 1915 ch. 237, 1915 Neb Laws 554 (repealed 1929). Under the provisions of the 1915 Sterilization Act, the Board of Examiners created by the Act was required to examine any individual eligible for discharge or parole from the institution at Beatrice. If after examination the individual was found to be (1) capable of reproduction, (2) likelihood that offspring would inherit mental retardation, and (3) the offspring would likely become “a social menace”, then sterilization would be a mandatory condition before freedom from Beatrice.

¹¹ Act of April 14, 1915 ch. 131 § 1, 1915 Neb. Laws 294.

¹² The Nebraska Supreme Court in 1931 upheld the constitutionality of the Sterilization Act as amended in 1929 in the decision of *In re Clayton*, 120 Neb. 680, 684, 234 N.W. 630 (1931). The Court in *Clayton* starkly stated: “The legislative act before us is in the interest of the public welfare in that its prime object is to prevent the procreation of mentally and physically abnormal human beings. We think it is within the police power of the state to provide for the sterilization of feeble-minded persons as a condition prerequisite to release from a state institution.”. See Law of April 30, 1929 ch. 163, § 1 [1929] Laws of Neb. 564 (repealed L.B. 547 § 1, [1969] Laws of Neb. 3132). The United States Supreme Court earlier in 1927 had placed its imprimatur on sterilization. In the decision *Buck v. Bell*, 274 U.S. 200, 204 (1927), while upholding the constitutionality of sterilization, Justice Oliver Wendell Holmes opined, “It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains

Feeble-minded Youth at Beatrice became *de jure* when its name was changed to the Nebraska Institution for the Feeble-minded with its new objective to provide “custodial care and humane treatment for those who are feeble-minded; **to segregate them from society** (emphasis supplied); to study to improve their condition; to classify them; and to furnish such training in industrial mechanics, agriculture, and academic subjects as fitted to acquire.”¹³ This change by the State of Nebraska in both the name and the stated objective of the facility significantly drove upward the population at the facility.

Between 1919 and 1959, a total of 5,420 individuals were admitted to the Beatrice facility.¹⁴ This state sponsored segregation of people with mental retardation at the Nebraska Institution for the Feeble-minded at Beatrice allowed families to dissociate themselves from their children or adult relatives with mental retardation.¹⁵ In 1942, the Beatrice facility changed its name for the third time when it became the Beatrice State Home. However, during the 1940s and 1950s, the Beatrice State Home resembled a warehouse more than a home as the population continued to swell and row after row of

compulsory vaccination is broad enough to cover cutting the Fallopian tubes... Three generations of imbeciles are enough.” See Bruinius, *Better for All the World: The Secret History of Forced Sterilization and America’s Quest for Racial Purity* (New York: Alfred A’ Knopf, 2006); and B. Mason, Segregating the Menace and the Chaining of Liberty: The Spectre of *Buck v. Bell* in the 21st Century (Missouri Valley History Conference, Omaha, Nebraska March 2006). It is an inescapable truth that at the Beatrice facility, as well as other facilities across the country, sterilization in the 1940s became not only an external means of social control but an important means of enlarging the authority of superintendents for the institution, apart from the stated medical purpose. Sterilization became a means of keeping higher functioning residents working for pennies in the institution understaffed during the labor demands of World War II. Thus, sterilization provided another means to ensure the survival of the custodial institution. Trent, Jr. *Inventing the Feeble Mind*, supra at 223.

¹³ *Out of the Darkness*, supra at 106.

¹⁴ Wolfensberger & Menolascino, Reflections of recent mental retardation developments in Nebraska I: A new plan. *Mental Retardation* 8(6) (1970): 20-28. Kurtz & Wolfensberger, Separation experiences of residents in an institution for the mentally retarded: 1910-1959. *American Journal of Mental Deficiency* 74(3) (1969): 389-396.

¹⁵ The segregating stigmatization continued even in death for those individuals confined at the Beatrice facility. Beginning in 1935, tombstones of deceased persons at the Beatrice facility’s cemetery were inscribed not with names but numbers. For the growing number of individuals at the Nebraska Institution for the Feeble-minded at Beatrice, who were viewed as a social menace in life by society and state policy makers, confined in custodial warehouses, forced to labor to support the very institution which denied them their humanity, they became forgotten with their life stories of hope, despair, love, and anguish buried under numbered tombstones at the Beatrice facility’s cemetery. Abandoned in life, they had become nameless in death.

beds in large dormitory style bedrooms became the norm.¹⁶ Death became the predominant mode of leaving the Beatrice facility.¹⁷ By the late 1960s, 2,300 people lived at the Beatrice State Home in facilities which a commissioned architectural engineering study found to be fit for only 800. The overcrowding led to the inevitable lack of training and habilitation for the residents who actually survived and remained warehoused at the Beatrice facility.¹⁸ Residents who were functioning at a higher level were dressing, bathing, feeding, and taking care of the more vulnerable who needed more assistance.¹⁹

By the summer of 1972, serious injuries and the incidents of abuse of the citizens still crowded into the facility were prevalent at an alarming rate. Inadequate numbers of poorly trained staff, overcrowding of the facility and reliance upon the residents to care for the other less able residents had created a dangerous and dehumanizing institution where habilitation remained illusory. During the summer of 1972, the Nebraska Association for Retarded Children (NebARC) attempted to meet with Governor J. James

¹⁶ Wolfensberger & Menolascino, Reflections of recent mental retardation developments in Nebraska I: A new plan. *Mental Retardation* 8(6) (1970): 20-28.

¹⁷Kurtz & Wolfensberger, Separation experiences of residents in an institution for the mentally retarded: 1910-1959.supra at 389-96; see also *Out of the Darkness*, supra at 24 and see also statement by Ms. Ollie May Webb who was committed to Beatrice at 19: "My family committed me at 19 to Beatrice. Beatrice was where people like me went when their families couldn't take care of them. When people went to Beatrice they were sentenced to life---with no hope, with no freedom and with no meaning. Their crime...being mentally retarded. But I was in the main building in the institution. I was taking care of all the little babies, wild babies, thou babies... I watched two little kids die in my arms." *Id.*, 55-56. The children admitted to the Beatrice State home suffered the highest mortality rate. Between 1920 and 1960, almost one-half (1/2) of the children admitted before the age of two died within 12 months; twenty-five percent (25%) died within the first three months of admission to the Beatrice State Home. Children died in droves under the dominant pathological medical model at the facility in Beatrice. Kurtz & Wolfensberger, Separation experiences of residents in an institution for the mentally retarded: 1910-1959.supra at 389-96.

¹⁸See *Report of the Human and Legal Rights Committee to the Board of Directors of the Association for Retarded Citizens* (Lincoln, Nebraska: Nebraska Association for Retarded Citizens, 1972). The *Report of the Human and Legal Rights Committee* detailed the deplorable conditions that existed at the Beatrice State Home in July 1972. See also: *Into the Light: Report of the Nebraska Governor's Citizens' Committee on Mental Retardation* (Lincoln, Nebraska: Nebraska Department of Public Institutions, 1968). *Into the Light* is the summary, highly critical of the dehumanizing conditions at the Beatrice State Home, of the lengthy report of the Citizens' Committee appointed by Governor Norbert T. Tiemann. See: *Report of the Nebraska Governor's Citizens' Committee on Mental Retardation* Vol. I and Vol. II. (Lincoln, Nebraska: Nebraska Department of Public Institutions, 1968).

¹⁹*Out of the Darkness*, supra., 57-59; 86-87; 141.

Exon to seek solutions to the increasingly deteriorating and dehumanizing conditions at the Beatrice State Home. The Governor refused to even meet with NebARC. In the fall of 1972, after Governor Exon's failure and default to even consider the plight of the 1,347 people enduring the dehumanizing conditions of their confinement at the Beatrice State Home, the United States District Court of Nebraska became the hope of those who languished at the Beatrice State Home.²⁰

On September 28, 1972 five persons confined at the Beatrice State Home filed a class action complaint in the United States District Court of Nebraska alleging that the State of Nebraska and its officials, by their failure to provide them with individualized habilitation plans, sufficient staff, and a safe environment, deprived them of liberty and their privacy and dignity under the Due Process Clause of the Fourteenth Amendment to the United States Constitution. The five residents, who had been ignored long enough by state officials, further alleged that their confinement at the Beatrice State Home constituted a violation of the Equal Protection Clause of the Fourteenth Amendment because individuals with similar disabilities were being habilitated in a system of community programs far less restrictive of personal liberties and substantially superior as to the level of habilitation than at the Beatrice State Home. Finally, they contended that the deplorable and dehumanizing conditions they were forced to endure at the Beatrice State Home constituted cruel and unusual punishment prohibited by the Eighth Amendment to the United States Constitution.²¹

²⁰ Id., 86; 166; 182.

²¹ *Horacek v. Exon*, 357 F. Supp. 71, 72 (D. Neb. 1973) (Memorandum and Order on Motion to Dismiss); Complaint in *Horacek v. Exon*, Civil No. 72-L-299 (Filing 1). The State of Nebraska filed a motion to dismiss the complaint which District Court Judge Warren Urbom denied on March 23, 1973. The State of Nebraska later filed a motion for summary judgment. Judge Urbom, while certifying the case as a class action, on June 5, 1974 also denied the motion for summary judgment and granted the National Center for Law and the Handicapped and NebARC amicus status, *Horacek v. Exon*, Civil No. 72-L-299 (Memorandum and Order of Motion for Summary Judgment, Declaring

On October 31, 1975, Judge Schatz, after a fairness hearing, entered a consent decree approving a settlement agreement between the class of private plaintiffs, the United States of America and the State of Nebraska which had been reached earlier on August 6, 1975 during lengthy and extended negotiations after the trial had commenced in July of 1975.²²

The *Horacek* consent decree recognized the constitutional right of individuals with mental retardation at the Beatrice State Developmental Center²³ to be protected from physical and psychological harm while in the custody of state officials, and their constitutional right under the Fourteenth Amendment to habilitation, which is the least restrictive of their personal liberty. The consent decree approved the reduction of the population from approximately 1,200 to a “goal” of 250 within three years under the supervision of the Nebraska Mental Retardation Panel mandated by the consent decree.²⁴

The State of Nebraska, with legislative rejection of funding for the Nebraska Mental Retardation Panel, in 1976 attempted to circumvent and obstruct the enforcement

Class Action and Granting Amicus Status June 5, 1974). On March 25, 1975, the original five plaintiffs who had courageously demanded of state officials that their constitutional rights be recognized and protected, no longer stood alone when Federal Judge Albert Schatz allowed the United States Department of Justice, Civil Rights Division to intervene as a plaintiff with them. The authority and resources of the Federal Government now stood side by side with them in their struggle for equality and liberty. *Horacek v. Exon*, Civil No. 72-L-299 (Application to Intervene as Party Plaintiff of March 10, 1975 and Order Granting Intervention as Party Plaintiff March 28, 1975); See also Mason & Menolascino, The Right to Treatment, supra at 165 ftnt.178; *Out of the Darkness*, supra 164-168.

²² Settlement Agreement of August 6, 1975, *Horacek v. Exon*, Civil No. 72-L-299 (D. Neb., consent decree approving settlement agreement entered October 31, 1975).

²³ July 1, 1975 the Beatrice State Home became the Beatrice State Developmental Center

²⁴ *Horacek v. Exon*, Civil No. 72-L-299 (D. Neb., consent decree entered October 31, 1975). The consent decree required Governor Exon, who had refused to even meet with NebARC in the summer of 1972, to form the Nebraska Mental Retardation Panel to prepare a statewide plan to address the population reduction goal and the timeframe necessary to achieve that goal; identify the method by which the reduction was to be achieved; establish assessment teams to evaluate each individual at the Beatrice State Developmental Center; and prepare individualized evaluations, treatment plans and placement recommendations. Furthermore, any new capital construction at the Beatrice facility needed to be approved only to habilitate the residual population under the terms of the consent decree. Settlement Agreement of August 6, 1975, *Horacek v. Exon*, Civil No. 72-L-299 (D. Neb., consent decree approving settlement agreement of August 6, 1975 and incorporating its provisions entered October 31, 1975).

of the constitutional rights of the citizens confined at the Beatrice State Developmental Center.²⁵

On April 6, 1979, newly elected Governor Charles Thone filed with the District Court an alternative plan (Thone I Plan) to implement the provisions of the 1975 consent decree. The initial Thone plan was amended and supplemented on June 28, 1979 (Thone II Plan).²⁶ By 1985, the population at the Beatrice State Developmental Center had decreased to 452 residents, almost a 66% decline from the inception of the *Horacek* litigation in 1972. Additionally, units for people with developmental disabilities at the Hastings Regional Center and the Lincoln Regional Center operated by state officials had been shut down.²⁷ The Beatrice State Developmental Center had assumed a “lesser” role in Nebraska with state planners and officials and its primary purpose was to *support rather than supplant* the community-based services.²⁸ This purpose never left the conceptual stage of state planners as BSDC, during the late 1980s and through the 1990s, remained constant in its population and static in its institutional culture.²⁹

²⁵ In September of 1976, the Department of Justice, joined by the private plaintiffs, returned to the courtroom to enforce the provisions of the consent decree of 1975. In February of 1978, Judge Schatz amended the consent decree and created a three person Nebraska Mental Retardation Panel under the Court’s supervision to develop a Plan of Implementation to finally implement the provisions of the consent decree of 1975.

²⁶ After the United States and the private plaintiffs filed objections to Thone I and Thone II Implementation Plans, the final State of Nebraska’s Implementation Plan was filed with the United States District Court on October 9, 1980, almost five years after the entering of the consent decree. The private plaintiffs withdrew their objections to the amended State of Nebraska Plan. However, the United States continued to object to provisions in the amended State of Nebraska Plan. On September 28, 1981, the District Court denied the Department of Justice’s objections and adopted the amended Thone five-year plan of Implementation. *The Plan of Implementation*, Nebraska Department of Institutions (Omaha, Nebraska: Cockle Printing, 1980); see also *Out of the Darkness*, supra, 168-169, 178-184. Frohboese and Sales, Parental Opposition to Deinstitutionalization: A Challenge in Need of Attention and Resolution 4 Law and Human Behavior 1, 31-35 (1980).

²⁷ *The Plan of Implementation Summary Report*. (Lincoln, Nebraska: Nebraska Department of Institutions, 1985).

²⁸ *Id.*

²⁹ Programmatically, state officials with BSDC remained predictable and cautious with few innovative models designed to integrate and return individuals to the community. Staff shortages continued during this period of time as the rural location of the facility and the low salaries were still less than desirable in attracting professionals and skilled direct care workers to the facility. Staff shortages have consistently plagued the Beatrice facility. Those shortages are a significant contributing factor in failure of the facility to meet the standard of professional practices required under federal regulations. See N. Hicks, “Beatrice center in staffing crisis” *Lincoln Journal Star* (May 8, 2007). Marvin, “Worse than Wal-Mart” Letter to Editor, *Omaha World Herald* (May 24, 2007). According to Mike

As the new century dawned, the persistent problems of staff shortages, residents with greater behavioral demands, the lack of innovative and creative solutions to the needs of the residents living at BSDC, the absence of integrative approaches and utilization of community resources, and an administration isolated and dissociated from the residents with whom it was entrusted to protect and treat remained embedded and combined into the downward spiral documented in the CMS investigations from 2001 through 2007.

The static and stagnant nature of the facility's officials with its focus on institutional preservation, reminiscent of earlier efforts in the early and mid 20th Century, was reflected in the fact that during the twenty plus years from 1985 to 2007 the Beatrice State Developmental Center has reduced its 1985 population by less than 100 residents while its budget which was \$17, 523,479.00 in 1985 has nearly tripled, ballooning to \$50, 226,416.00 for current fiscal year 2007-2008.³⁰ The immediate jeopardy findings by CMS in the Fall of 2006 and the Spring of 2007 meant that over \$28,000,000.00 in federal funds could have been withheld. The departure from generally accepted professional standards of care by state officials at BSDC in 2006 and 2007, by failing to meet the minimally accepted professional standards in the regulatory requirements of 42 C.F.R. § 483 Subpart I, shook the very core of the facility's long standing justification for its continued existence: humane treatment and care which could be obtained nowhere else.³¹

Marvin, the Executive Director of NAPE/AFSCME Local 61 AFL-CIO, the starting wage for Developmental Technicians at BSDC is \$8.54 per hour. Of the 655 full-time bargaining unit workers at BSDC, 285 make under \$11.00 per hour.

³⁰ Sec. 121, Laws _____ LB 321.____. For a funding history of the Beatrice State Developmental Center and Community-Based Mental Retardation Programs from 1969 to 1980 see *Out of the Darkness*, supra 165.

³¹ See generally CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (survey completed 09-29-2006) (1-413) and CMS Statement of Deficiencies and Plan of Correction for the

**A CHRONOLOGY OF FAILURE: A REVIEW OF THE CENTER FOR
MEDICARE AND MEDICAID SERVICES' SURVEYS OF THE
BEATRICE STATE DEVELOPMENTAL CENTER 2001—2007**

As of October 2007 the Beatrice State Developmental Center (BSDC), the State of Nebraska's owned and operated intermediate care facility for individuals with mental retardation (ICF/MR), is home to approximately 350 residents with developmental disabilities who possess diverse abilities and functional levels. Over three-fourths (3/4) of the residents at BSDC have speech/language impairments; one-third (1/3) have visual impairments, with thirty-two (32) being totally blind; and almost one-half (1/2) are non-ambulatory and non-mobile. Additionally, approximately two-thirds (2/3) of the residents have seizures or a history of seizures, with nearly ten percent (10%) uncontrolled. Nearly fifty percent (50%) of the residents at BSDC receive medications to control injurious behaviors to themselves or others, and over forty percent (40%) have significant behavioral needs requiring behavior program intervention. The population at BSDC is aging, with two-thirds (2/3) of the residents between forty-six (46) to sixty-five plus (65+) years of age. However, there are approximately seventeen (17) residents under the age of twenty-two (22). Almost all the residents at BSDC have guardians, and slightly fewer than ten percent (10%) are committed under court order. The facility provides support and services to persons who have a dual diagnosis of developmental disabilities and mental illness. BSDC also operates a program licensed as a Center for

Beatrice State Developmental Center (survey completed 09-20-2006) (1-192). Compare the 2007 stated goal of "providing services at BSDC that are of high quality and which protect the rights of individuals served there, while promoting independence and *ensuring that their health and safety needs are met*" with the purpose clause of the 1885 legislation establishing the facility at Beatrice, "Besides shelter and protection, the prime object of said institution shall be to provide **special means of improvement (emphasis supplied)** for that unfortunate portion of the community who were born or by disease have become imbecile or feeble-minded, and by a **wise and well adapted course of instruction (emphasis supplied)** reclaim them from their helpless condition, and through the **development of their intellectual faculties (emphasis supplied)**, fit them as far as possible for usefulness in society. "Three-Year State Plan" (Lincoln, Nebraska: State of Nebraska Health and Human Services System Developmental Disabilities System, June 2007) Goal A-2, page 10; §2 Act of March 5, 1885, ch. 52, 1885 Neb. Laws.

the Developmentally Disabled (CDD) at the Hastings Regional Center (the “Bridges” program) and a hospital unit on the grounds of the state institution at Beatrice, Nebraska. Each of these facilities and programs is licensed separately.

BSDC, as an ICF/MR, is subject to periodic surveys and inspections by the United States Department of Health and Human Services, Center for Medicare and Medicaid Services (CMS). In September of 2006, CMS conducted a comprehensive survey to assess BSDC’s compliance with federal ICF/MR regulations which is a required condition for participation in the Medicaid Program. On October 2, 2006 CMS found that BSDC was not in substantial compliance with the applicable federal rules, regulations and interpretive guidelines for accepted professional standards of care in a substantial number of critical areas, and the conditions at the facility constituted an **immediate jeopardy to resident health and safety**.³² During the course of a follow up survey on April 19, 2007 CMS surveyors again found that BSDC was not in substantial compliance with the applicable federal rules, regulations and interpretive guidelines for accepted professional standards of care in seven out of eight critical areas, and the conditions at the facility constituted **immediate jeopardy to resident health and safety**.

This current repeated inability of state officials to protect and treat the residents at BSDC who are entrusted to their care did not materialize overnight. CMS has surveyed BSDC repeatedly. Our research and analysis of CMS survey reports has focused on the period 2001-2007. The CMS survey reports during this time period clearly document that the critical and substantial failures to meet accepted professional standards of care at BSDC cited in the October 2006 and April 2007 CMS survey reports are merely the most

³² Use of the term “professional” in this context means not only physicians, psychologists, nurses, social workers, therapists, etc. but includes any and all direct care staff, therapy assistants, etc., who provide care, treatment and services under the supervision and direction of such individuals.

recent in years of failures that have been known and tolerated by state officials with the responsibility to protect and habilitate residents at BSDC. The problems and failures at BSDC are systemic, chronic, and have persisted for years.³³

In the following section, we provide a brief summary of the major findings contained in the reports of CMS surveyors during surveys conducted at BSDC in 2001, 2003, 2004, 2005, 2006, and 2007. Later sections of the report will address in greater detail the findings contained in the CMS reports of surveys at BSDC in 2006 and 2007.

November 2001. CMS surveyors found facility policy and procedure allowed staff with substantiated allegations of physical abuse or neglect which constituted a serious threat to clients to return to work in direct care of residents. This finding resulted in the Facility Administrator being notified that an **immediate jeopardy situation** was found to exist. Surveyors also found the facility did not ensure the rights of all residents, including the right to file complaints and the right to due process. The facility also failed to: 1) provide compensation to clients who work for the facility; ensure that residents have the right to communicate, associate and meet privately with individuals of their choice; and ensure that residents have the right to retain and use appropriate personal possessions and clothing; 2) notify promptly a resident's parents or guardians of any significant incidents or changes in the resident's condition, including serious illness, accident, death, abuse or unauthorized absence; 3) develop and implement written policies and procedures that prohibit mistreatment, neglect or abuse of residents; 4) ensure that all allegations of mistreatment, neglect or abuse, as well as injuries of unknown source are reported and thoroughly investigated; and that the results of all investigations are reported immediately in accordance with state law (within 5 working days of the incident); 5) ensure the prevention of further potential abuse while an investigation is in process; 6) ensure that appropriate corrective action was taken in situations where the allegations were verified; 7) adequately monitor programs and failed to secure the required consent of the client, parents or legal guardian; and 8) ensure that the resident records documented the use of less

³³ Stoddard, M. "Agency was told of flaws in care" Omaha World Herald (October 7, 2006); Stark, S. "Patient care criticized at Beatrice State Developmental Center: Federal Investigation finds patients jeopardized" www.NewsNetNebraska.org (December 31, 2006). Earlier critical reports of the lack of care at the State operated residential facility for individuals with developmental disabilities have been documented for almost forty years. These investigations evidenced similar, if not identical, deficiencies at BSDC as the 2006 and 2007 investigations did. See e.g., *Report of the Human and Legal Rights Committee to the Board of Directors of the Association for Retarded Citizens* (Lincoln, Nebraska: Nebraska Association for Retarded Citizens, 1972). The *Report of the Human and Legal Rights Committee* detailed the deplorable conditions that existed at the Beatrice State Home in July 1972. See also: *Into the Light: Report of the Nebraska Governor's Citizens' Committee on Mental Retardation* (Lincoln, Nebraska: Nebraska Department of Public Institutions, 1968). *Into the Light* is the summary, highly critical of the dehumanizing conditions at the Beatrice State Home, of the lengthy report of the Citizens' Committee appointed by Governor Norbert T. Tiemann. See: *Report of the Nebraska Governor's Citizens' Committee on Mental Retardation* (Lincoln, Nebraska: Nebraska Department of Public Institutions, 1968) Vol I and Vol II.

restrictive techniques prior to the use of more restrictive techniques. It was also noted that techniques to manage inappropriate resident behavior were being used as a substitute for an active treatment program.ⁱ

January 2003. CMS surveyors found that the facility failed to assure that abuse or neglect allegations were reported immediately, almost one-half of allegations of abuse or neglect logged by the facility were not reported to state authorities as required by law, and the facility failed repeatedly to investigate serious injuries to residents, such as fractures of unknown origin and peer-on-peer sexual behavior.³⁴

April 2003. The facility failed to meet the timelines of the Plan of Correction it had submitted, continued to fail to investigate injuries of unknown or suspicious origins for several residents, failed to conduct follow up investigations, failed to promptly investigate and discipline staff for hitting a vulnerable resident, and took several weeks to complete investigations of abuse and neglect which were to be completed within five (5) working days.ⁱⁱ

October 2003. The facility still failed to thoroughly investigate incidents and complete investigations in a timely manner, despite repeated promises in its previously submitted Plans of Correction to remedy its deficiencies. Surveyors found a repeated pattern of systemic deficiencies in the area of incident management and included detailed findings of the neglect of two of the residents' medical needs who had Gastric (G) and Jejunostomy (J) feeding tubes resulting in the death of one resident due to peritonitis and a "near miss" of another by peritonitis as a result of staff misplacement of the feeding tubes.ⁱⁱⁱ

January 2004. The evidence mounted that the officials at BSDC were not implementing their previous assurances to CMS of immediately reporting all injuries of unknown origins suffered by the residents living at BSDC. The facility failed to assess and implement safeguards to protect residents from documented self-injurious behavior. A behavior management plan did not exist for a resident who, for over a year, exhibited documented self-injurious behaviors, including slapping himself, banging his head, biting his arms, or aggressive behaviors to other residents and staff, slapping peers and staff, pinching staff and peers, and property destruction.^{iv}

³⁴ CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 01-31-2003) pgs 1-59; See § 28-372 of Adult Protective Services Act, Neb. Revised Statutes requires any employee of any facility licensed by the Department of Health or Human Services who has reasonable cause to believe that a vulnerable adult has been subjected to abuse ...shall report to the appropriate law enforcement agency or to the department. See also: § 28-715 (Abused or Neglected Child Registry) requires that reports of suspected abuse or neglect be filed in special state Abused or Neglected Child Registry.

Mid March 2004. BSDC failed to ensure immediate reporting of abuse, neglect, and injuries of unknown origins. Nursing staff failed to take appropriate nursing actions examining a resident in respiratory distress at 9:15 a.m. and took no action but instead told the staff, “He’s fine, there’s nothing wrong with him, quit telling him he’s sick.” The resident remained in respiratory stress from 9:15 a.m. until the nurse returned to his room between 12:15 p.m. to 12:20 p.m. for a Nebulizer treatment at which time he quit breathing and turned blue. Artificial respiration was initiated, a Code Blue was called, and the resident was transported to community hospital where he was pronounced dead.^v

Late March 2004. CMS cited BSDC for the facility’s failure to meet the dietary needs of the residents living there.^{vi}

October 2004. The facility was placed in an **immediate jeopardy situation** due to a resident being seriously hurt after a fall from a mechanical lift and the facility failed to initiate interventions by training or re-training care staff in the use of mechanical lifts.^{vii}

However, the warning signs of serious problems at BSDC grew more ominous in 2005 as a CMS surveyor found that the facility was not providing adequate supervision of the people living at the facility.

May 2005. The facility failed to remedy the lack of supervision resulting in behavior management plans not being current and appropriate to meet the habilitation needs of the residents. Inadequate supervision resulted in increased elopements from the facility by residents (one of whom had a previous history of inappropriate sexual behaviors) and one resident was allowed to roam the halls at night consuming food/edibles for over a year. The same resident had an outdated treatment plan that included the use of edibles as behavioral reinforcement two years after he had received a G-tube and could no longer consume edibles. A resident with a well documented and known history of pica disorder was allowed to go unsupervised throughout the facility and nearly died after two days of vomiting because of swallowing a cork taken from another resident’s room. A resident, with a history of choking that resulted in his being placed on a pureed diet, was fed a peanut butter sandwich against the dietary plan in place for over two years. He began choking, lapsed into unconsciousness and was hospitalized in the intensive care unit at the Community Hospital for four days.^{viii} When the facility did investigate an allegation of abuse and neglect, it consistently and continually failed to follow its own policies of suspending from the workplace staff members who were being investigated for abuse and neglect.^{ix}

August 2005. Incidents of staffing shortages, verbal abuse of vulnerable adults, and team managers neither investigating nor reporting incidents of abuse and neglect were found to be prevalent and still not in compliance with federal requirements.^x

October 2006 and April 2007. The facility was cited for: (1) not meeting the applicable federal rules, regulations and interpretive guidelines of accepted professional standards of care in a substantial number of critical areas necessary to protect the residents from harm; and (2) not meeting the applicable federal rules, regulations and interpretive guidelines for acceptable professional standards of care in a substantial number of critical areas necessary to ensure active treatment for those residents. More importantly, CMS found that the practices and conditions at BSDC in the Fall of 2006 and the Spring of 2007 were so deficient that a finding of **immediate jeopardy** was necessary. Those findings and their consequence will be discussed in much greater detail in subsequent sections of this report.

As a result of our extensive review and analysis of CMS survey reports of BSDC from 2001 to 2007 the evidence demonstrates clearly that state officials have repeatedly:

- Failed to provide adequate supervision.
- Failed to report or investigate immediately abuse and neglect allegations.
- Failed to suspend offending staff members.
- Failed to implement behavior management programs.
- Failed to provide for proper nursing care resulting in unnecessary pain for a resident who died.
- Failed to address nutritional and dietary deficiencies.
- Failed to provide adequate numbers of appropriately trained direct care staff, and
- Failed to follow BSDC's own policies.

Beginning in the Fall of 2006 and continuing through the Spring of 2007, this pattern of failure has become an indictment of indifference against the state officials responsible for the protection and treatment of vulnerable residents at BSDC entrusted to their care.

CHRONOLOGY OF NEBRASKA ADVOCACY SERVICES' INVESTIGATION

Upon notification of the serious and substantial finding by the Center for Medicare and Medicaid Services (CMS) of **immediate jeopardy** in October 2006 Nebraska Advocacy Services (NAS), acting under its authority within the Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. § 15001 et seq., immediately contacted CMS, the ARC of Nebraska, and the Acting Administrator of the Beatrice State Developmental Center (BSDC) for documentation of the CMS findings. On October 5, 2006 three (3) days after the CMS finding, NAS received a faxed copy of partial findings by CMS. Although partial in nature, an examination and analysis of the preliminary findings raised substantial concerns that systemic deficiencies existed at BSDC that placed people residing there at a risk of serious harm or danger.

NAS determined that the preliminary findings demanded a thorough and comprehensive investigation of alleged violations of both constitutional and federal statutory rights of persons with developmental disabilities residing at BSDC. The following is a simple chronology of our investigations:

Early October 2006. After completing a preliminary analysis, NAS formally requested the entire CMS survey report and the plan of correction prepared by BSDC in response to the findings in the CMS survey report from the State of Nebraska. Simultaneously, NAS began negotiations with the State of Nebraska for an Access Agreement to the BSDC facility, its residents and staff, and to review the records of BSDC residents. Only by this complete access to the facility, residents, staff, and records at BSDC, could NAS fulfill its federal mandate and monitor the safety of those residents.

November 2006. Negotiations on access to BSDC proceeded rapidly and on November 2, 2006, a month after the initial CMS report, an Access Agreement was approved between NAS and the State of Nebraska. With approval of the Access Agreement, NAS initiated its new presence at the facility. NAS legal advocacy staff met with the Acting Administrator and visited all residential and programmatic units to question staff and

observe the residents living there. NAS also requested demographic information and the identification of the residents and their guardians referenced in the CMS reports. The State of Nebraska complied expeditiously with all of NAS' requests for data and resident information.

December 2006. On December 9th the NAS Chief Executive Officer, Litigation Director and Director of Legal Services met with parents of BSDC residents to explain what NAS had done to date and planned to do in the future to not only meet its federal mandate but to advocate and protect those residents living at the facility. NAS legal advocacy staff returned to BSDC for an additional on-site inspection.

January 2007. All incident reports of any physical injury that occurred during December, 2006 and January, 2007 were reviewed by the NAS Litigation Director and Case Advocate. Hundreds of reports, filling eight (8) three-ring binders, were examined to establish a base line so that NAS could understand and verify the accuracy of the levels of severity contained in the BSDC reporting procedures. Furthermore, all BSDC policies and procedures were analyzed by the same NAS personnel to obtain an understanding of the operational aspects of BSDC. NAS staff received and began analyzing the entire October, 2006 CMS survey report. NAS staff began identifying specific problematic areas and troublesome units with either a higher degree of the number of incidences of injuries or a higher degree of severity of the injuries.³⁵

February 2007. NAS staff continued to analyze the entire CMS survey of the Fall of 2006.

March 2007. NAS received the 450 page BSDC response and plan of correction for review and analysis.

April—June 2007. NAS reviews BSDC response and plan of correction. Staff continues to visit BSDC and investigate cases of abuse and neglect based on probable cause.

July 2007. NAS received and analyzed the CMS survey report of April of 2007 and the BSDC response and plan of correction submitted the middle of July of 2007.

³⁵ As a result of the directed focus by NAS staff, one unit at BSDC (108 Kennedy) was identified as experiencing unacceptable high levels of peer-to-peer aggression, a high number of violent incidences, and a high degree of staff turnover and absenteeism. NAS met with the BSDC Acting CEO, the State of Nebraska's Ombudsman's Office and the 108 Kennedy Treatment Team to communicate NAS' concerns and to present our intention to monitor the treatment plans of three (3) residents for whom we shared significant concerns. Those heightened concerns resulted in NAS opening active cases for the three residents. As a result of the meetings, personnel changes were made on the unit and NAS continues to represent those three (3) residents.

August 2007. NAS opened cases for further specific investigations on twenty-six (26) additional residents. Individual records are being received and continue to be reviewed by NAS for these twenty-six (26) residents.

Since November 2006 NAS legal advocacy staff has made bimonthly inspections and on-site reviews at BSDC. During this time NAS legal advocacy staff has interviewed direct care staff, professional staff, residents and administrators at the facility. NAS staff has compiled extensive records, conducted detailed document reviews and met regularly with the supervisor of the four (4) recently hired abuse investigators.³⁶ NAS continues to receive monthly summaries of the more serious level of incident reports. In addition, the NAS Director of Litigation conducted several extensive on-site inspections, including interviews with facility staff, people who reside at the facility and facility administrators. He has reviewed and analyzed over eleven (11) months of individual resident records, facility records, incident and investigation reports, facility policies and procedures, as well as the CMS survey reports for 2001, 2003, 2004, 2005, 2006, and 2007. He has also consulted with nationally recognized experts in the residential treatment of persons with developmental disabilities.

During the course of our investigation, NAS staff visited people living at BSDC in their residences, at activity areas, and during meals. Our review and analysis of relevant state and facility documents has been extensive, including policies and procedures, as well as medical records, medication records, treatment plans, restraint records, and behavior management plans for people residing at the facility. We have reviewed and analyzed countless pages of: 1) incident reports of physical injuries, sexual assaults, verbal abuse, and deaths; and 2) reports of investigations for physical injuries, sexual assaults, verbal abuse, elopement, and deaths for the individual living units. We

³⁶BSDC is currently attempting to fill two (2) vacant investigative positions due to resignations.

have also examined other historical documents, including legislative enactments, budget appropriations, executive and legislative and citizen group reports or recommendations, and prior court pleadings and reports arising from the class action right to treatment litigation involving conditions at BSDC: *Horacek v. Exxon*, 357 F. Supp. 71 (D. Neb. 1973) (Consent Decree entered October 31, 1975).

The monitoring of BSDC by NAS remains ongoing at the current time. As a preliminary matter, NAS notes that BSDC is staffed predominately by dedicated individuals who are genuinely concerned for the well-being of the residents in their care. However, the evidence demonstrates unequivocally that they are underpaid, undertrained and overworked by state officials. NAS is now issuing its preliminary findings and recommendations in this report due to the persistent and chronic nature of the problems existing at the Beatrice State Developmental Center.

CONSTITUTIONAL AND STATUTORY OBLIGATIONS OF STATE OFFICIALS AT THE BEATRICE STATE DEVELOPMENTAL CENTER

State officials must provide citizens who live at the Beatrice State Developmental Center (BSDC) with supports and services in accordance with the state's federal constitutional obligations. see: *Youngberg v. Romeo*, 457 U.S. 307 at 322-323 (1982).

The U.S. Supreme Court has recognized that persons with developmental disabilities who reside in state facilities, such as BSDC, have a "constitutionally protected liberty interest in safety." *Youngberg* at 318. The Court held that the state "has the unquestioned duty to provide reasonable safety for all residents" within the institution. *Id.*, at 324.

Furthermore, persons with developmental disabilities residing at BSDC have a constitutional right to "minimally adequate training." *Youngberg* at 322. Specifically,

“the minimally adequate training required by the Constitution is such training as may be reasonable in light of [the institutionalized person’s] liberty interests in safety and freedom from unreasonable restraints.” *Youngberg* at 319. An essential component of habilitation treatment for persons with developmental disabilities is the regular provision of activities designed to help them develop new skills and practice skills already learned.

The test of whether a facility, such as BSDC, has provided adequate minimal levels of constitutionally required care and treatment depends on if that facility’s practices substantially depart from generally accepted professional judgment. *Youngberg* at 323. Evidence that a facility has engaged in practices that constitute a substantial departure from accepted professional standards of care is available by both the opinions of experts knowledgeable in the profession and violations of national regulatory standards or guidelines.

The Center for Medicare and Medicaid Service’s (CMS) regulations require that Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) must protect residents with developmental disabilities from harm, provide adequate staffing, protect them from abuse, and ensure the provision of **active treatment** to reduce dependence on drugs and physical restraints. In particular, 42 C.F.R. § 483.420 (a) (5) requires that the facility “ensure that clients are not subjected to physical, verbal, sexual or psychological abuse or punishment”. 42 C.F.R. § 483.430 (d) (1) requires facilities to “provide sufficient direct care staff to manage and supervise residents”, while 42 C.F.R. § 483.420 (6) requires facilities to “ensure that clients are provided active treatment to reduce dependency on drugs and physical restraints”.

**FINDINGS OF VIOLATIONS OF THE CONSTITUTIONAL RIGHTS
OF CITIZENS LIVING AT THE BEATRICE STATE
DEVELOPMENTAL CENTER BY STATE OFFICIALS**

Nebraska Advocacy Services (NAS) incorporates, as an integral part of its own findings and conclusions of constitutional violations at the Beatrice State Developmental Center (BSDC), those findings and conclusions of the Center for Medicare and Medicaid Services (CMS) in its investigations of the Fall of 2006 and the Spring of 2007. Both sets of findings demonstrate that practices at BSDC substantially departed from accepted professional standards of care in violation of federal regulations. Observations, analyses, inspections, record reviews, and consultations with experts by NAS since November of 2006 confirm the earlier CMS findings. We present an overview and summary examination of the CMS findings from October of 2006 and April of 2007 that is further supplemented and illustrated by more recent findings from the ongoing investigation at BSDC being conducted by NAS.

FINDING I

***Nebraska State Officials Have Failed and Continue to Fail to Protect
Vulnerable Individuals at the Beatrice State Developmental Center from
Physical, Verbal, Sexual, and Psychological Harm and Abuse
in Deprivation of Their Constitutional and Statutory Rights.***

Nebraska Advocacy Services (NAS) finds that certain conditions and practices at the Beatrice State Developmental Center (BSDC) violate the constitutional and federal statutory rights of citizens who live at the facility. Specifically, NAS finds that residents living at BSDC suffer harm and the continued risk of harm from the facility's failure to keep them safe.^{xi} The facility regularly subjects the vulnerable residents who live there

to physical abuse, neglect, and serious physical injury.³⁷ This is a recurrent and chronic problem pervading the institutional culture from the CEO down to the direct care staff. It continued to blatantly manifest itself even after state officials provided later assurances that it had been eradicated.³⁸ NAS further finds that there exists a pattern and practice, extending for years, that state officials have not protected people living at BSDC from harm and the risk of harm.

The level of harm and violence for residents living at BSDC continues to escalate as a consequence of historically chronic staff shortages, inadequately trained staff and lack of professional assistance at the facility. This persistent reality impacts not only the immediate safety issue, but also the ability of state officials to provide active treatment, which requires a continuous process for the development, implementation, monitoring, assessment, and modifying of behavior interventions.

³⁷ This finding by NAS is not recent. In 2002, NAS successfully settled a wrongful death action against the State of Nebraska for the negligent failure by state officials at BSDC to protect Kristine Everitt, a 43 year-old woman with a well-documented history of seizures, who died while left unattended in a bath at the facility. She drowned while alone and unsupervised for 15 to 25 minutes in a whirlpool bath on February 15, 1999. Her death did not need to happen. Seventy-five days before her death on February 15, 1999, she had been left alone and unsupervised in the same whirlpool. At that earlier failure of supervision she had a seizure and had to be resuscitated. Kristine Everitt, according to records at BSDC, had multiple seizures daily at the facility. As part of the settlement, which included a significant monetary award for her estate and dismissal of the State of Nebraska's claim for reimbursement for her care, state officials agreed to erect a memorial to Kristine on the grounds of BSDC in her memory and as a reminder of the devastating consequences of the failure to meet their primary duty to protect individuals at BSDC. *E. Dean Everitt Sr., Personal Representative of the Estate of Kristine Everitt, Deceased v. State of Nebraska*, Case No. C100-25 (District Court of Gage County) (Settled 2002).

³⁸ In the Fall of 2006, the CMS survey on placed the facility at Beatrice in immediate jeopardy for this systemic failure. Id., 43-72. BSDC in its plan of compliance provided assurances that the failures to meet acceptable professional standards had been eliminated. However, in April 2007, a CMS survey again placed BSDC in immediate jeopardy because, "The facility's system to prevent and detect abuse, neglect and mistreatment failed to adequately protect individuals from harm or potential harm. **The facility did not thoroughly investigate all allegations of abuse, neglect, mistreatment and injuries of unknown source; the facility failed to ensure that sufficient safeguards were in place during the course of these investigations; and the facility failed to take appropriate corrective action when a violation was verified** (emphasis supplied)". CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-192) 2-3.

**A. Center for Medicare and Medicaid Services Findings of
Violations of Federal Regulations and Standards at the
Beatrice State Developmental Center in October of 2006 and April 2007**

In October, 2006 the Center for Medicare and Medicaid Services (CMS) found that the Beatrice State Developmental Center (BSDC) failed to meet the requirement of § 1905 (d) of the Social Security Act and substantially departed from the accepted professional standards of care as established in federal regulations for Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). Specifically, CMS found that BSDC and state officials had departed from federal regulations in **seven out of eight critical areas** (emphasis supplied) that directly impacted the lives of all residents living at the facility. Two of those areas relate to the repeated failure of state officials to protect the residents from harm: 1) BSDC violated 42 C.F.R. § 483.10 (Governing Body and Management) because the facility’s governing body failed to exercise general operating direction over the facility which CMS found potentially affected all residents living at BSDC;^{xii} and 2) BSDC violated 42 C.F.R. § 483.20 (Client Protections) in that state officials at the facility failed to ensure that residents were free from abuse, neglect and mistreatment.

The above findings resulted in the identification of two **immediate jeopardy** situations which had not been removed at the time CMS left on September 29, 2006: 1) “the facility failed to ensure that clients were free from abuse and mistreatment ... potentially affecting all 367 clients in the facility”; and 2) “the facility failed to develop and implement written policies and procedures that prohibit abuse and neglect as evidenced by the lack of adequate supervision provided to prevent client abuse... potentially affecting all 367 clients.”^{xiii} State officials at the facility also violated the rights of BSDC residents in that they “*failed to ensure due process* (emphasis supplied)

for clients with rights restrictions and failed to obtain informed consent for restrictive practices” for residents at the facility. Additionally, the facility failed to promote community participation and integration for individuals in the residence which had the potential to affect all residents in the facility.^{xiv} In the major areas of failure to protect BSDC residents, CMS continued to document the mounting list of failures by state officials to protect the vulnerable citizens in their custody. Specifically, state officials had failed to:

- develop, establish, maintain, and monitor a system to investigate all allegations of abuse, neglect, mistreatment and injuries of unknown sources at BSDC in a timely manner;
- report *102 of 193 injuries of unknown origin* in a three-month period to the administrator;
- conduct a thorough investigation of allegations of abuse and neglect as well as injuries of unknown origin;
- ensure that sufficient safeguards were in place during the course of these investigations and to take appropriate corrective action when a violation was verified or substantiated;^{xv} and
- put safeguards in place during investigations of allegations of abuse and neglect and failed to take appropriate corrective action for injuries of unknown origin and allegations of abuse, neglect, and mistreatment.

These failures, in the judgment of the federal CMS surveyors, directly impacted all residents at BSDC.^{xvi}

In April of 2007 surveyors for the Center for Medicare and Medicaid Services (CMS) returned to survey the Beatrice State Developmental Center (BSDC) and found that the facility failed to meet the requirement of § 1905 (d) of the Social Security Act and substantially departed from the accepted professional standards of care established by federal regulations for Intermediate Care Facilities for the Mentally Retarded (ICFs/MR).

Specifically, CMS found that BSDC and state officials had again continued to violate federal regulations 42 C.F.R. § 483.20, as they had six months earlier, by failing to ensure **client protections** (emphasis supplied) that directly impacts the lives of all residents living at the facility³⁹. Specifically, state officials again failed to:

- implement and monitor a system to prevent abuse, neglect and mistreatment and failed to adequately protect residents from harm or potential harm;
- investigate all allegations of abuse, neglect, mistreatment and injuries of unknown source;^{xvii}
- conduct thorough investigations;^{xviii}
- ensure that sufficient safeguards were in place during the course of these investigations and take appropriate corrective action when a violation was verified or substantiated;^{xix}
- complete and report investigations to the administrator within the required five (5) day time period;⁴⁰ and
- take appropriate corrective actions when a violation was verified.⁴¹

CMS also found a new and critically important violation by those state officials in that they **failed to recognize client-to-client abuse as “abuse”** (emphasis supplied) in that they did not require specific levels of injury to be reported to the administrator.^{xx} This failure impacted all residents at BSDC.

³⁹ CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-192); Letter with Enclosures of Immediate Jeopardy from Centers for Medicare & Medicaid Services to Lawrence Pezley, Acting Chief Executive Officer, Beatrice State Developmental Center (April 24, 2007).

⁴⁰ Id. 56-62. CMS reported that many investigations languished for as long as two weeks. Id.

⁴¹ Id. 53-56; 62-98. CMS found that state officials took no corrective actions for over 50% of the injuries of unknown origin which occurred in March of 2007. Between January 17, 2007 and April 20, 2007, state officials took no corrective action for 25% of injuries of unknown origin. Id. 62.

B. Further Examples of Violations of Federal Regulations Supportive of Nebraska Advocacy Services' Findings of Deprivations of Constitutional Rights at the Beatrice State Developmental Center

During the course of our ongoing investigation of conditions at the Beatrice State Developmental Center (BSDC) we documented that many of the practices of state officials at BSDC that violated and departed from the standards of care in 42 C.F.R. § 483.20 and 42 C.F.R. § 483.440, have continued unabated after state officials submitted their last Plan of Correction to the Center for Medicare and Medicaid Services (CMS) in July of 2007. Of significant concern to Nebraska Advocacy Services (NAS) is the repeated failure⁴² of state officials at BSDC to: 1) report, thoroughly investigate, and take immediate corrective action; 2) initiate appropriate interventions involving the significant number of injuries of unknown origins; and 3) decrease the escalating peer-to-peer violence that continues to permeate the facility.⁴³ Despite assurances contained in the Plan(s) of Correction submitted to CMS by state officials in 2001, 2003, 2004, 2005, 2006, and 2007 to bring BSDC into compliance with the federal standards of professional care, they have failed to do so and still do depart substantially from those accepted standards of care.⁴⁴

⁴² Repeatedly, in 2001, 2003, 2004, 2005, 2006, and 2007 CMS surveyors cited State officials for this systemic failure.

⁴³ Evidence indicates that individuals who are non verbal at BSDC continue to be at risk of significant bone fractures. See the following similar incidents: **(Incident #013)**-Non-verbal individual has broken humerus of unknown cause; **(Incident #056)**-Non-verbal individual has fracture of surgical neck of left humerus and fragment fracture of the humeral head; see also: **(Incident # 008)**- Fracture of arm of unknown cause; **(Incident #020)**-Fracture of left foot of unknown cause. Investigation noted that roommate had a similar fracture. Since September 27, 2007, four individuals at BSDC have suffered bone fractures. Two suffered fractures of the legs with the cause of "unknown origin". One other individual suffered a broken finger. NAS is still attempting to ascertain what bone(s) were fractured of the fourth individual. The individuals who have the fractures of the legs and the individual who has the unknown fracture are **non-verbal**.

⁴⁴ Compare the CMS surveys of 2003, 2004, and 2005 with those of 2006 and 2007 and the same failure to thoroughly investigate is cited by the federal surveyors. CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 01-31-2003) pgs 1-59; CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-17-2003) pgs 1-13; CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 10-09-2003) pgs 1-54; CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 01-22-2004) pgs 1-24; and CMS Statement of Deficiencies and Plan of Correction for the Beatrice

NAS has included a brief sample of illustrative cases which, in our judgment, demonstrates and supplements the more than 600 pages filled with countless individual examples in the 2006 and 2007 CMS survey reports. These examples clearly demonstrate the facility has failed to meet its fundamental responsibility under the United States Constitution and federal statutes and implementing regulations to provide treatment and protect the residents living at the facility from harm, rape, or sexual assaults.⁴⁵ The significant importance of the following sample of illustrative cases is that they establish the continuing violations of constitutional rights, federal regulations and the departure from accepted standards of professional care by state officials responsible for BSDC. These brief summaries were prepared by NAS staff; however, NAS disagrees with the conclusion that there was neither abuse nor neglect in several of those investigations. The examples are presented in a chronological sequence in order to illustrate the scope and extent of the continuous violations at BSDC. We believe these incidents serve to corroborate that the problems at BSDC are sweeping in their scope

State Developmental Center (Survey Completed 05-11-2005) pgs 1-14, with CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) and CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-192).

⁴⁵ CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) pgs 43-105 documents a rape of an 18 year old female in BSDC school reading room by an 18 year old male who had a well documented history of sexual predation and impulse control and for whom BSDC failed to supervise under the pre-admission requirement "that he was being placed at BSDC for supervision and structure due to sexual activity and impulse control and required 24 hour awake visual supervision." Privacy and human dignity dissipate in staff convenience. CMS surveyors describe its demise, "Two staff was observed with client 33 in the bathroom. The door to the bathroom was open and staff verbally prompted client 33 to take her robe off. The two staff assisted client 33 in taking her clothes off and client 33 stood naked in the bathroom in full view of clients and staff that passed by. Staff then proceeded to assist client with a shower while the bathroom door remained open."Id. 76. Individuals at BSDC are sexually assaulted by staff. The CMS surveyor details, "A technician went into the restroom in the coed dining area and discovered client 56 sitting on a stool in a stall while (Former Employee 1), Food Service Aide, was masturbating (Client 56) who had an erection...The client indicated that this was the second incident in which (former employee) had touched him....The investigation revealed a second allegation of abuse by former Employee 1 that involved client 56; this allegation was noted by both the Administrator and the investigator. The Administrator confirmed that there was no further investigation into this second allegation." Id. 117-118. NAS notes that a sexual assault of vulnerable adults in the custody of state officials is a felony in Nebraska. No felony prosecution ensued of the food service aide. Nor is there evidence that the information of the observed sexual assault was provided to either the County Attorney of Gage County or the State Patrol. See also: **(Case # 012)-April 6, 2007**-Peer-on-peer sexual assault while staff members played cards.

from the *alpha* of critical, life-endangering staff abuse and/or neglect, to the *omega* of staff shouting at individuals. It is this spectrum of illustrative cases that we believe evidences a culture of dismissive disrespect and devaluation for the personhood of individuals living at the facility.

JANUARY 2007

(Incident #001)—A woman who resides at BSDC was receiving assistance in bathing from a staff member. The staff member noticed that the woman’s breast area and naval appeared to be shaved. She was taken to the Beatrice Community Hospital for a possible sexual assault examination. The Beatrice Community Hospital report indicates that the woman possibly did have her naval and breast area shaved. BSDC investigation concluded: Staff where she lives had a heightened awareness of incidences where other people living on the unit had been shaved in their pubic area without medical authorization. Her loss of hair could have been from using adhesive tape for her briefs or from topical lotions that were used to clean her feeding tube; no abuse or neglect occurred.

(Incident #002)—A man who resides at BSDC was eating an apple for a snack, tried to eat it, and then spit it on the floor. Staff did not clean up the apple mess from the floor and the man has a history of eating food off the floor. BSDC investigation concluded: Staff was neglectful in this situation.

FEBRUARY 2007

(Incident #003)—Staff observed a discoloration on the left calf of a woman who resides at BSDC. In an internal BSDC investigation, the investigator questioned whether she received this “bruise” while staff was “holding her down to change her brief.” The investigation concluded: Staff did not neglect or abuse her in receiving this injury. The investigation did not have a conclusive explanation as to how she acquired the injury.

(Incident #004)—BSDC conducted an internal investigation when a web moderator of a website contacted Nebraska Department of Health and Human Services and reported that a woman was posting on her website and reporting about abuse and neglect of people who receive services at BSDC. The staff member writing on this website talked specifically about two people being abused by staff members. The staff member alleged two other staff members were propping a chair in front of a woman’s door so they would be alerted if she attempted to leave her room. Another allegation stated that staff would sit on a woman in order to “calm her down.” A third allegation stated that a woman woke up upset and the staff “dealt with” her. BSDC investigation concluded: Abuse occurred in posting this information on a website, failing to report verbal abuse, and for propping a chair in front of a woman’s bedroom door.

(Incident #005)—A BSDC staff person wrote in a web-based “journal” that she felt like killing a woman who resides at BSDC. She also called this woman a “psycho lady” in the journal. These statements by the BSDC staff person were posted on a website. Also this woman who receives services from BSDC was wrapped up in her blanket to the point that she was not allowed to free her arms. BSDC investigation concluded: Abuse on the part of staff members that were restraining her with the blanket.

(Incident #006)—A woman who resides at BSDC was grabbed without a gait belt and roughly placed in her wheelchair by a staff member. She fell to the floor and injured her lower right leg and left ankle. BSDC investigation concluded: Staff member physically abused her.

MARCH 2007

(Incident #007)—A man who resides at BSDC has a doctor’s order for the use of a mechanical lifting device when making transfers from one surface to another. The method the staff used was a method that was taught in staff orientation. BSDC investigation concluded: Staff did not neglect him when they transferred him without a lift. The investigation also noted the reporting staff member did not like the staff member she was alleging used the improper lifting methods.

APRIL 2007

(Incident #008)—A man who resides at BSDC was found to have a fractured arm. One staff member reported seeing another direct care staff member transferring him without the use of the doctor-ordered mechanical lift. The reporting staff member was concerned about whether this may have caused his broken arm. BSDC investigation concluded: Neglect did take place.

(Incident #009)—A man who resides at BSDC was assigned one-on-one supervision for sexually inappropriate behaviors, physical aggression, and property destruction. He reported on this night he was able to roam freely around the residence. Instead of providing supervision, the direct care staff played a card game leaving several people unsupervised. BSDC investigation concluded: Staff was neglectful in failing to supervise.

(Incident #010)—Staff was required to provide 30-minute checks on two men who reside at BSDC while they are asleep. These checks are the result of a previous incident in which one of the gentlemen sexually assaulted the other. A direct care staff member documented that she conducted the checks when she did not. BSDC investigation concluded: She had neglected the men.

(Incident #011)—A man who resides at BSDC reported to staff that he was sexually assaulted by a peer the night before in his bathroom. The aggressor in this situation had been assigned one-on-one supervision, but was not being adequately supervised. The man who was assaulted was to have staff check on him every 30 minutes

while he was asleep, however this did not happen. The BSDC investigation showed that while the alleged assault took place, staff members were playing cards at a table. BSDC investigation concluded: A “sexually inappropriate” act took place. However, the investigation could not determine whether or not the act was consensual or an act against the man’s will. The investigation found that the staff did neglect this man. The report further concluded that if staff had provided appropriate supervision, the incident would have been interrupted or prevented.⁴⁶

(Incident #012) April 7, 2007—A man who resides at BSDC fractured his right humerus. Staff noticed him refusing to eat and that he complained of pain in his arm. He was taken to the Beatrice Community Hospital where a doctor found that he had fractured his right humerus most likely through blunt force trauma. In an internal investigation, BSDC was unable to find documentation or reports from staff or the man that provided information of the blunt force trauma that could have caused his fracture. BSDC concluded: There was no abuse or neglect. The man is non-verbal and could not participate in the investigation.

(Incident #013) April 12, 2007—A staff member pushed a man into the wall and was also seen “teasing” the man by attempting to take his food from his plate. The same staff member had been accused of physically abusing him three other times in the past nine months. In the previous three investigations, the staff member was not found to be physically abusing the man. BSDC investigation concluded: Staff member did abuse him both physically and mentally in this incidence.

(Incident #014)—A staff member at BSDC held a man’s head back against the headrest of his wheelchair, forced a spoon into his mouth, and held a washcloth over his mouth to prevent him from spitting out his medication. While she did this, she stated, “You’re not going to do this to me.” Two other staff members observed this incident, but did not immediately intervene or report it to appropriate personnel. BSDC investigation concluded: Staff member administering the medication was physically and verbally abusive to the gentleman. The other two staff members were found to have neglected him by failing to intervene and appropriately report the abuse.

(Incident #015)—A woman who resides at BSDC requires enhanced supervision when food and liquids are present. She has a G-tube and it could be life-threatening if she ingests food or liquids. During mealtime, a staff member was initially providing appropriate supervision. The staff member was then called upon to assist with another task and focused her attention elsewhere. When she turned her attention back, the woman was ingesting a cup of gelled liquids. BSDC investigation concluded: Staff member neglected her.

⁴⁶ NAS disputes the BSDC investigator’s characterization of sexual assault of an individual at BSDC as a “minor” injury. Such a characterization reflects, in the judgment of NAS, continued social devaluation of individuals at BSDC. See Osburn, *An Overview of Social Role Valorization theory*. 1(1) The SRV Journal 4, 4-5 (2006).

(Incident #016)—A man who resides at BSDC experienced multiple fractures to his left great toe when a door on his wardrobe unit fell on it. The man’s father had sent replacement hinges to BSDC; however, six weeks later, when the incident occurred, the hinges had not been attached. BSDC investigation concluded: Staff was neglectful in not ensuring that hinges to the wardrobe were replaced.

(Incident #017)—A non-verbal woman who resides at BSDC moved off the toilet and a staff member noticed she left blood on the toilet. The staff member checked her genitalia and found a one-inch laceration on the inside of her left labia. The non-verbal woman was first seen at the BSDC Outpatient Clinic and then sent to the Beatrice Community Hospital which concluded that the injury was a suspected mechanical trauma. BSDC staff reported to the hospital staff that this woman with a disability sits down with a “plop” on the toilet seat. BSDC investigation concluded: No abuse or neglect on the part of BSDC staff. This non-verbal person with a disability was not able to participate in the investigation.

MAY 2007

(Incident #018)—A man who resides at BSDC was required to wear a one-piece pajama due to a history of chewing on his colostomy bag. One staff refused to comply with this requirement due to the difficulty of dressing him in the one-piece pajama and her concern that this would also restrict him from masturbating. BSDC investigation concluded: Staff member was found to have neglected this man.

(Incident #019)—A man who resides at BSDC left his home and was found at an apartment complex adjacent to the BSDC campus 20 minutes later. He is required to have one-on-one supervision. He also has a Wanderguard for elopement issues. The staff members were not supervising him appropriately at the time of the incident. The alarm went off when he opened the door and staff was unable to turn off the alarm as they did not know the code. BSDC investigation concluded: Staff neglect for not providing appropriate supervision.

(Incident #020)—A man who resides at BSDC was found to have a swollen and bruised left foot during his evening bath. When X-rays were performed it was discovered that he had a fractured left foot. The way in which he fractured his left foot is unknown. BSDC investigation concluded: Staff was not found to be neglecting him; however, the investigation did note that a similar unknown injury took place with his roommate.

(Incident #021)—A man who resides at BSDC was under routine supervision, meaning that staff was not required to provide any further supervision during meals. He has a G-tube and it can be life-threatening if he ingests food or liquids. He ingested a ¼ glass of grape juice. BSDC investigation concluded: Staff did not neglect him; however, the supervision level was changed to one-on-one when foods or liquids are present.

(Incident #022)—A man who resides at BSDC was placed in an unapproved Mandt hold by a security guard and a staff member. During this incident, staff that were aware that the guard and a staff member were using inappropriate techniques failed to intervene and stop the hold. The security guard had received advanced training in Mandt and still was not aware of the inappropriateness of his technique. BSDC investigation concluded: Staff had abused the man in the use of the unauthorized Mandt hold. The investigation also showed that staff had neglected him when they did not intervene upon discovering the guard was using inappropriate techniques.

(Incident #023)—A man who resides at BSDC received seven different medications that were prescribed for a peer in his home, as well as his own prescribed medication. The staff member who administered the medication was highly frustrated that evening. The man was admitted to Outpatient Clinic and monitored for the evening. His blood pressure fell to 70/40 as three of the medications mistakenly given were for high blood pressure. BSDC investigation concluded: Staff member neglected the man.

(Incident #024)—A woman who resides at BSDC was seen outside at the end of the sidewalk without supervision. She was discovered to still have her napkin tucked into her shirt and her spoon from lunch. She was to be on “enhanced supervision” within sight of staff at all times. Staff members at her home were not aware that she was gone. BSDC investigation concluded: Staff neglect for not providing appropriate supervision and the Team Leader was cited for not reporting the incident as an incident of abuse or neglect.

(Incident #025)—During a BSDC internal investigation, three separate issues were reported to Human Resources:

1. A direct care staff member had reported another staff member had been sleeping on third shift.
2. A man who resides at BSDC made a suicidal verbalization and a direct care staff member asked to call the psychologist on duty to talk to him. The psychologist replied that he would not talk to the man because the man was being “manipulative.”
3. A man who resides at BSDC made a homicidal verbalization. When the direct care staff member called the manager for assistance, the manager told her to “take care of it yourself.”

BSDC investigation concluded: Neglect took place regarding the staff member sleeping on third shift, but that there was no neglect in the other two incidences.

(Incident #026)—A man who resides at BSDC pinched another resident. BSDC conducted an internal investigation. The report included the name of the staff member who was assigned to supervise the man. The investigation concluded: Staff member listed to have neglected the man was not at work at the time in question, thus neglect did not take place. The investigator did conclude, however, that the direct care staff member in the man’s home did not know who they were supervising and what the supervision requirements were.

(Incident #027)—A man who resides at BSDC was scheduled to have dental work done under general anesthesia. The procedure was explained to his guardian at a team meeting before the procedure was performed. His guardian (mother) was aware that one tooth may have to be pulled and numerous cavities filled. During the procedure, the dentist determined that it would be more beneficial to pull three teeth. The dentist then stopped the procedure to allow the man’s social worker to contact his guardian for consent to pull more teeth. When the social worker was unable to contact the guardian, she contacted the guardian’s husband (the man’s father), whom the social worker believed was a co-guardian. The husband granted consent, however, he was not the co-guardian. The guardian called after the procedure and reported that she would have not given consent to pull three teeth. BSDC investigation concluded: The social worker neglected the man by not obtaining appropriate consent from his guardian.

(Incident #028)—A woman who resides at BSDC injured her hand when she engaged in self-injurious behavior of hitting herself on her head with her hand. She was to receive one-on-one supervision within five to eight feet when the incident happened. BSDC investigation concluded: Shift manager neglected her by not having appropriate safeguards in place.

(Incident #029)—A woman who resides at BSDC injured her back when she was pushed by another resident. A BSDC internal investigation showed that after this incident occurred, the other resident was placed on visual supervision by the Treatment Unit Manager. This manager failed to inform the staff of the change in supervision level, which meant that appropriate safeguards were not in place to prevent future incidences. BSDC investigation concluded: The manager neglected both of these women.

JUNE 2007

(Incident #030)—A woman who resides at BSDC was found walking around outside her work area. The staff member assigned to her had just finished feeding her through her feeding pump. After eating, she lay down for a nap and the staff member went to do paperwork in the office. This woman is ordered not to lie down for 30 minutes after eating via her feeding pump. BSDC investigation concluded: Neglect did not take place due to a shift change and uncertainty of who was assigned to her at the time she eloped.

(Incident #031)—A woman who resides at BSDC was being “buddy lifted” by two staff members from the commode to her bed. While making this transfer, she hit her head on her headboard causing a one-inch red area on her head. BSDC investigation concluded: Neglect due to her requiring the use of a mechanical lift for all transfers.

(Incident #032)—A man who is non-verbal and resides at BSDC had been participating in activities at the Carston Center on the BSDC campus. While in the gym at the Carston Center, he reached for a metal electrical outlet. A staff member responded by pushing the man’s arm down with her foot. When he removed his hand from the outlet, it was deeply cut and covered in blood. He required emergency surgery at Bryan LGH-

West in Lincoln to repair a lacerated tendon in his long finger and a laceration on his index finger. At the time BSDC conducted an internal investigation, it was not certain whether he would regain full use of his long finger. BSDC's investigation concluded: Staff member physically abused this man. The investigation further concluded that another staff member neglected him, as she had his supervision card at the time and was not providing him with appropriate supervision.

(Incident #033)—A woman who resides at BSDC was eating a grilled cheese sandwich that was cut up into bite-size pieces per her dietary requirements. While she was eating, she began choking, lost consciousness, and required the use of the Heimlich maneuver. Staff members called 911 and began CPR as they were unable to dislodge the food in her throat. A physician's assistant was able to suction out the food from her throat. BSDC investigation concluded: Neglect did not take place as the food was cut as required and staff responded appropriately to the medical crisis.

(Incident #034)—A man who resides at BSDC had an ileostomy bag that had come open and needed to be changed. None of the staff members on duty were trained to do this task, and the nurse was called. While waiting for the nurse, one staff member assisted the man to a bathroom stall, helped him remove some of his clothing, and left him on the toilet, unsupervised for 30 minutes. When the nurse found him, he had feces all over his body, his clothing, and the bathroom stall. BSDC investigation concluded: Staff members on duty neglected this man in not helping him to clean up even though they could not provide direct assistance with the ileostomy bag.

(Incident #035)—A man who resides at BSDC was discovered unsupervised outside in his wheelchair by a staff member from another area. It is unclear how long he was outside without supervision. The staff member that was assigned to him was required to know where he is at all times, as he likes to leave his home. BSDC investigation concluded: Neglect did take place. The staff decided to give permission for him to use a Wanderguard. This is the fourth time he has left without supervision since January 1, 2007.

(Incident #036)—A man who resides at BSDC was assaulted by a staff member when the staff member was trying to restrict his access to food in the kitchen. The staff member was told to "keep him out of the kitchen" due to a history of his "stealing food." As he attempted to get into the kitchen, the staff member pushed him out of the way causing him to fall back and hit his elbow. BSDC investigation concluded: Staff member physically abused him.

(Incident #037)—A man who resides at BSDC is required to have enhanced supervision for a history of elopement and sexually inappropriate behavior. He left his home and was unsupervised for 15 minutes. Enhanced supervision requires knowing where he is and what he is doing at all times. He had been placed in Mandt holds two times before this for behavioral incidences. BSDC investigation concluded: Staff did not neglect him. The investigator notes that as soon as the staff member realized he was not around, the staff member began looking for him.

(Incident #038)--A woman who resides at BSDC was left in her bed, unsupervised, while all the other residents and staff went to the Carsten Center for activities. A housekeeper came around to clean and discovered that she was left on the unit by herself. When the staff at the Carsten Center realized they had left her on the unit alone about 30 minutes had elapsed. BSDC investigation concluded: Staff was neglectful in failing to supervise. An Acting Team Leader was also found to be neglectful when he did not respond appropriately when it was discovered that this woman with a disability had been left at the unit.

(Incident #039)—A manager from Beatrice Supermarket reported that a staff member flicked a man who resides at BSDC on the head and overheard the staff member tell him to “shut up.” BSDC investigation concluded: Staff member verbally abused him, but did not physically abuse him. The staff member provided an “explanation” as to why the manager at the supermarket may have seen what looked like her “flicking” the man’s helmet.

(Incident #040)—A woman who resides at BSDC had bruises on her arm after a peer bit her. BSDC investigation concluded: Both women were receiving appropriate supervision and appropriate safeguards were implemented after the incident. No abuse or neglect was found.

(Incident #041)—A man who resides at BSDC was receiving assistance with bathing from a direct care staff member. The staff member realized that she had forgotten the mechanical lift and went to retrieve it, leaving the man unsupervised in the bath. He is required to have one-to-one supervision while bathing because he may “jump or throw himself” while in the bathing device. BSDC investigation concluded: Staff member did not neglect him and that it was not clear in the on-call documentation that he was not allowed to be left unsupervised.

(Incident #042)—A man who resides at BSDC was walking toward a staff member who put her feet up to block his path. The staff member told him to “get away from me” and made physical contact with him with one of her feet. BSDC investigation concluded: Staff member physically and verbally abused him.

(Incident #043 and Incident #044)—Two men who reside at BSDC reported similar incidences during group therapy that staff had elbowed them and were disrespectful. Both incidences included allegations of staff excessively restraining them in some way. BSDC investigations for both incidences concluded: Physical abuse did not take place. However, both investigations did note that a staff member accused of abusing these men had eight allegations of abuse or neglect from five different individuals during his employment at BSDC.

(Incident #045)—A man who resides at BSDC reached out and grabbed and pinched a peer’s arm. He was to be provided one-on-one supervision within five feet. He needed this level of supervision because of past incidences of aggression toward others. BSDC investigation concluded: Staff had neglected him because they were not providing the appropriate level of supervision at the time of the incident.

JULY 2007

(Incident #046)—A woman who resides at BSDC was placed in her bed in the early evening while two staff took other residents to an outing. The other staff that stayed behind did not check on her while she was in bed. When she was finally checked almost five hours later, she was found to be soaked in urine (including her clothes, blankets, and mattress). BSDC investigation concluded: Staff neglected her.

(Incident #047)—A direct care staff member reported observing another staff member falling asleep on second shift. The staff member who fell asleep was holding a supervision card for a man and was required to be within five to seven feet because of his aggressive behavior. BSDC investigation concluded: Staff member neglected him and all other people who live in that home. The reporting staff member was also found to have neglected the people she served because she woke the other staff member up about five times before reporting the neglect.

(Incident #048)—BSDC conducted an internal investigation to examine a Team Leader’s failure to report an incident of peer-to-peer violence and failure to implement safeguards to prevent further incidences of violence. BSDC investigation concluded: Team Leader neglected the two people involved in the incident in the failed responsibilities of reporting and implementation of safeguards.

(Incident #049)—A direct care staff member was supervising 11 people when an investigator approached the group because of her concern that a man was attempting to harm himself. When the investigator approached the staff member about the situation, the staff member was aggressive and hostile. BSDC investigation concluded: The direct care staff member was not neglecting the people under his supervision and the investigator was reprimanded for approaching the situation like she did.

(Incident #050)—A man who resides at BSDC reported that he injured his back when a staff member pushed him off his bed. BSDC investigation concluded: Staff member did not assault him and the injury took place when he fell off of his bed onto a plastic container. The investigation did note that the staff member has had five allegations of abuse and neglect in the last year. The staff member was found to have verbally abused other people who reside at BSDC and had shown disregard for another person’s dignity and respect.

(Incident #051)—A man who resides at BSDC grabbed a gelled cup of tea while out of staff supervision. He was previously placed on one-to-two supervision while in the presence of food and liquid, allowing for staff to immediately intervene. He has a G-tube and is not allowed to have food or liquids. Staff had not passed out supervision cards at the beginning of the shift and only passed them out when this incident took place. BSDC investigation concluded: He was neglected.

(Incident #052)—A direct care staff member reported to her supervisor that she overheard a Social Worker talk to a woman who resides at BSDC in a disrespectful way. The staff member stated that she heard the Social Worker talk in a similar fashion days before. BSDC investigation concluded: The Social Worker did not verbally abuse the woman, as it was clearly stated in her Behavioral Modification Plan to use a stern voice with her. The staff member was reprimanded for not making a report sooner, as she stated she had heard a similar interaction several days before.

(Incident #053)—A woman who resides at BSDC was allowed to go to the beauty shop unsupervised when her supervision level was such that she required someone to go with her. When staff realized that she went without supervision, a direct care staff member went to sit with her and walk her back to her home. BSDC investigation concluded: There was no neglect, as there was a meeting taking place at this time that changed her supervision requirements. This change would allow her to travel independently.

(Incident #054)—A woman who resides at BSDC was placed in mechanical restraints without the authorization of the Qualified Mental Retardation Professional (QMRP). The BSDC staff person made two phone contacts with the QMRP and thought she had authorization to place this woman with a disability in restraints. The BSDC investigation concluded this staff person had abused/neglected her in not receiving appropriate authorization.⁴⁷

(Incident #055)—A woman who resides at BSDC was discovered in the kitchen eating corn chips. She has a G-tube and is not able to have food or liquids. The staff member that was assigned to her care put her to bed, completed his paperwork, and left without letting other staff know that he was leaving. Monitoring devices that were to alert staff to her movements were not in place. BSDC investigation concluded: Staff member assigned to this woman was negligent.

(Incident #056)—A non-verbal woman who resides at BSDC was discovered to have bruising on her left arm. Staff took her to the Beatrice Community Hospital and she received x-rays. It was determined that she had a fracture of the surgical neck of the left humerus and a fragment fracture of the humeral head. Hospital staff described the injury as a “shattered shoulder caused by blunt force trauma.” BSDC investigation concluded:

⁴⁷ CMS surveyors cited state officials at BSDC in 2006 for misuse of mechanical and chemical restraints. See CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) 301-303, 315-327.

Undetermined cause of injury. BSDC staff was not found to be abusive or neglectful to the non-verbal woman with a disability who could not participate in the investigation.

(Incident #057)—A 76 year old woman who resided at BSDC died while in their care. BSDC staff had assisted her to bed after her evening snack. While eating her snack, she vomited approximately two cups of kool-aid but was able to get up and go to bed. She had a history of reflux and had 12 incidences of reflux from March 2007 to July 2007. After going to bed, staff heard a loud noise coming from her room, and upon entering found her on the floor unresponsive and not breathing. Staff contacted emergency personnel and began performing CPR. When EMS arrived they asked if there was a Do Not Resuscitate (DNR) order. A DNR order was found; however, a new guardian had been appointed in April 2007 and a new DNR had not been signed by the guardian. Life-saving measures were discontinued under an invalid DNR order. BSDC investigation concluded: The Social Worker in charge of the woman's care had neglected her by not having a valid DNR order. An autopsy is being completed at this time.

(Incident #058)—A staff member left for a break which left one staff member to supervise seven people. The women who live in the home require increased supervision levels at times. BSDC's internal investigation concluded that the staff member who left on break neglected the women in her care.

(Incident #059)—BSDC investigation of several people who reside at BSDC found various states of neglect by a third shift staff person. The staff person was found to have neglected these individuals even though he reported that they were all attended to during his shift.

- One person was found to have wet bedding and her brief partially off.
- A second person was found to have dried feces on him and his bedding (top sheet, fitted sheet, and comforter).
- The third person was found wearing a dry brief but his bedding was wet and there were soiled wipes on his bed.
- A fourth person had his brief under him and he was wet.
- A fifth person was found to have a wet spot on his bed that was the size of a basketball.
- A sixth person was found completely soiled in his brief.

(Incident #060)—A woman who resides at BSDC was found in the women's locker room having a seizure. She was on enhanced supervision-visual supervision during waking hours. When another staff member found her in the locker room, she was not being supervised. BSDC investigation concluded: The staff member assigned to her neglected her by not providing appropriate supervision.

AUGUST 2007

(Incident #061)—A woman who is non-verbal and who resides at BSDC went to the BSDC Outpatient Clinic for an examination when a staff member saw a red area in her pubic region. BSDC investigation concluded: Because she had a history of using objects, such as dolls for masturbating, this “may be the cause of injury” and that the staff did not abuse or neglect her. However, because she is non-verbal, she was not able to communicate what happened or how it happened, and thus she could not actively participate in the investigation process.⁴⁸

(Incident #062) August 3, 2007--A man who resides at BSDC was discovered in his bedroom with a toothbrush covered in feces, feces on his tee-shirt, shorts, and bed sheets. He was transported to the Beatrice Community Hospital for an examination. He does not like doctors and the Emergency Room doctor told the staff to take him home as it was too much of a “hassle” to try and examine him. During the BSDC investigation, staff reported that the man has a history of inserting his fingers in his rectum. BSDC investigation concluded: He was not sexually assaulted and that he inserted the toothbrush into his own rectum. BSDC staff was not found to have neglected this man with a disability because supervision was being provided.⁴⁹

(Incident #063)—A staff member reported overhearing another staff member call a man who resides at BSDC a “freak” and said, “fuck you” when the man said he did not want to go to bed. BSDC investigation concluded: Verbal abuse did take place. During the investigation, the reporting staff member stated that she had overheard this same staff member verbally abuse people who receive services at BSDC in the past.

(Incident #064)—A man who resides at BSDC was discovered on the beginning of first shift with dried feces under his fingernails, covering his left hand, outside his briefs, on his sheet, surrounding his penis and scrotum, and matted to his pubic hair. A staff member reported that another staff member who was responsible for his care was “careless.” BSDC investigation concluded: The staff member neglected the man in his care. The staff member responsible for him had previously been written up for three other work deficiencies. In these deficiencies, the staff member reported very similar situations of leaving people in soiled briefs.

(Incident #065)—A man who resides at BSDC was not taken to the restroom, checked, or changed for 5 ½ hours during first shift. His clothes were wet with urine and he had feces coming out of his briefs. The staff member in charge of his home that day had just returned from a 5 ½ week suspension due to a finding of substantiated neglect on

⁴⁸ Although the facility was previously cited by CMS for its failure to ascertain the cause of the injury and the incident is marked as an “injury of unknown origin” the facility then compounds its initial deficiency by not initiating intervention measures to prevent it or similar injuries from occurring in the future. CMS found this failure to be in violation of federal standards as contained in the regulations. See CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-192) 2-3. CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) 43-72.

⁴⁹ It is logically impossible to claim that “appropriate” supervision of any kind would allow an individual in the care of the facility to insert a toothbrush into his rectum.

another person who receives services at BSDC. BSDC investigation concluded: Staff level of care was neglectful of the man's needs and "did not comply with ICF/MR level of care." Even though this was the staff member's second offense, the discipline involved "informal counseling" and she returned to work ten days later.⁵⁰

(Incident #066) Incident Observed by NAS Case Advocate—A man who resides at BSDC was able to gain access to food when the staff member assigned to him turned around and was not providing appropriate supervision. The man is on a restricted pureed diet. He went to the refrigerator and was able to gain access to a whole pie, an onion, and one other item. The NAS Case Advocate observed two BSDC staff members assisting him to sit by forcibly pushing him down by his head. The NAS Case Advocate reported the staff actions to the BSDC supervisor of investigators. BSDC investigation concluded: Abuse occurred in this incident. One of the staff members who pushed him down by his head was returned to work with the consequence of having "informal counseling and teaching component."⁵¹

(Incident #067) Incident Observed by NAS Case Advocate—A man who resides at BSDC was talking with a staff member. He called the staff member a jerk and the staff member replied, "no, you're the jerk." The staff member engaged in similar interactions for about 15 to 20 minutes. The same man kissed a female staff person on the cheek and a male staff member told him that he was going to call her boyfriend and have him "kick his butt." The same staff member told the man that he was going to have the female staff's boyfriend "take care of him." The NAS Case Advocate observed the incident and reported the staff actions to the BSDC supervisor of investigators. BSDC investigation concluded: Staff verbally abused this man in both incidences.

⁵⁰ BSDC has averaged nearly 100 vacant positions for months, necessitating significant overtime by existing staff and the shuffling of staff between residential units to cover for vacancies. Consequently, continuity of care in the implementation of individual habilitation plans has been severely compromised. Furthermore, from January 2007 thru August 14, 2007, 165 BSDC staff members were suspended pending investigations of allegations of abuse or neglect. Twenty-three (23) staff members have been suspended multiple times pending investigations. Investigators have substantiated abuse or neglect by 80 direct care staff or almost ½ of those investigations. Of those 80 direct care staff found responsible for abuse or neglect by BSDC's own investigators, ten percent (10%) have been found responsible multiple times. Investigations of abuse or neglect have been substantiated against 12 Team Leaders with two Team Leaders having multiple substantiations. Abuse or neglect has been substantiated against three nurses, the security chief, a treatment unit manager, a treatment team leader, and two social workers. *NAS Analysis of BSDC Staff Suspension from January 2007 to August 14, 2007*. NAS suggests that the chronic staff shortage preventing meaningful habilitation is also impacting on the extent of discipline imposed or not imposed by state officials at BSDC. State officials neither can suspend for long periods of time nor terminate repeat offenders without exacerbating the staff shortage crisis already approaching a meltdown. See N. Hicks, "Beatrice Center Staffing in Crisis", *Lincoln Journal-Star*, May 8, 2007.

⁵¹ The lack of meaningful discipline for a staff member manifesting deliberate indifference, in the presence of the NAS staff, to the dignity of an individual entrusted to his care further illustrates the conundrum of state officials at BSDC due to the staff shortage, lack of adequate training, and a culture embedded with stereotypic and dehumanizing views of the individuals living there. See Osburn, [An Overview of Social Role Valorization theory](#), 1(1) *The SRV Journal* 4, 7-8 (2006); Mason and Menolascino, [The Right to Treatment](#), supra at 135; See Wolfensberger (1976) *The Origin and Nature of Our Institutional Models* in R. Kugel and A. Shearer, eds., *Changing Patterns in Residential Services for the Mentally Retarded* (Washington, D.C.: President's Committee on Mental Retardation 1969) 63-143.

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(Incident #068)—A man who resides at BSDC was discovered to have eight broken ribs on September 6th when he was being treated for an upper respiratory infection. It was documented that on September 3rd he had fallen out of a Med Care sling while being transferred from his bed to a bath. At the time of the incident, he did not present any bruises or injuries and was seen by a nurse. He has a history of attempting to lunge out of the sling if he becomes highly excitable. BSDC investigation concluded: It was the doctor's opinion that the eight broken ribs were the result of a fall. The investigation reported that pictures were not taken after the fall in violation of BSDC Rules and Regulations. The man is non-verbal and was not able to participate in the investigation.

(Incident #069)—While in the stereo room with six residents, a staff member was found sleeping by another staff member. BSDC investigation concluded: None of the residents were receiving active treatment.

(Incident #070)—A woman who resides at BSDC reported to staff that another staff member raised her voice with her earlier in the day. The reporting staff member observed the other staff member at the elevator after the woman had reported the verbal abuse and questioned her about the woman's allegations. The staff member then raised her voice and told the woman "if you are going to talk about it do it in front of her." The reporting staff member informed the other staff member that her comments were inappropriate. BSDC investigation concluded: The staff member was "stressed due to working massive amounts of overtime."

(Incident #071)—A woman who resides at BSDC was fed via G-tube by a staff member who was not authorized or trained to hook up and administer nourishment through the G-tube. Another staff member observed this and reported the incident. During BSDC's internal investigation, this staff member informed the investigator that he had been allowed to do the same procedure at 207 Kennedy. This information was not confirmed by any other staff members. BSDC investigation concluded: The staff member's actions constituted neglect.

(Incident #072)—A staff member returned from an extended break due to working both first and second shifts on this day. The staff member was supervising five people, and before she left, asked to have another staff member take over their care. The staff member was gone from 1500 to 1615. When she returned, none of the residents had been changed, cleaned up, or readied for supper. A staff member found a woman to be wet with urine that had soaked through her clothes and had a loose bowel movement. A man was wet through his clothes and had to be changed. Another man had dried feces stuck on his bottom. He was also wet with urine and needed his clothes changed. BSDC's internal investigator noted that the three staff assigned at this time did not get along and had actually planned on retaliating against one another. BSDC investigation concluded: Although the residents had been neglected, their toileting assistance was within the established guidelines.

The examples above clearly evidence the continued departure from accepted professional standards of care at BSDC as required by federal regulations. NAS concludes that the chronic and persistent staff shortages are impacting the safety and habilitation needs of the residents. Direct care staff members are working massive amounts of overtime and double shifts. The inevitable consequence is that even basic sanitary needs of the residents at BSDC are being neglected to the detriment of their dignity.⁵² The dehumanization of these vulnerable citizens has continued unabated despite promises by state officials to meet federal regulations.^{xxi}

FINDING II

Nebraska State Officials Have Failed and Continue to Fail to Provide Active Treatment and Habilitation for Residents with Developmental Disabilities at the Beatrice State Developmental Center in Deprivation of Their Constitutional Rights.

As a result of our ongoing investigation, Nebraska Advocacy Services (NAS) has determined that certain conditions and practices at the Beatrice State Developmental Center (BSDC) violate the constitutional and federal statutory rights of citizens who live at the facility. Specifically, people who live at BSDC have a constitutional right to receive adequate care, training, and habilitation. The level of harm and violence for residents living at BSDC continues to escalate as a consequence of historically chronic staff shortages, inadequately trained staff and lack of professional assistance at the facility. On a weekly average, over 100 direct care staff positions remain unfilled at BSDC. This persistent reality impacts not only the immediate safety issue, but also the ability of state officials to provide active treatment, which requires a continuous process

⁵² Repeatedly, individuals at BSDC are being found soaked in urine and covered with feces due to the staff's inability to meet their basic sanitary needs. See: **(Incident Case #064)**—Individual found with dried feces underneath his fingernails, outside of his briefs, on his sheet, and covering his penis and scrotum, and matted in his pubic hair; **(Incident #065)**—Individual found soaked in urine and feces coming out of his briefs because responsible staff let him sit for 5 ½ hours; **(Incident #072)**; **(Incident # 034)**—Individual found smeared with feces after being left unattended on toilet for 30 minutes by staff.

for the development, implementation, monitoring, assessment, and modifying of behavior interventions.

Consequently, people who live at BSDC are neither being properly supervised nor receiving appropriate habilitation.⁵³ Citizens living at BSDC are denied their right to live in reasonable safety and to receive adequate habilitation to ensure their physical safety, freedom from physical injury, freedom from unreasonable restraint, prevention of regression and assistance in the exercise of their protected liberty interests.⁵⁴ In general we find that:

- The facility fails to provide a system of active habilitation that includes adequate assessments; developing, implementing, and monitoring individual programs; or encouraging an individual's choice and self-management.
- Citizens residing at BSDC do not receive consistent, continuous training to acquire behaviors necessary to function with as much self determination and independence as possible and to prevent regression or loss of current optimal levels of functioning.
- In the exercise of BSDC's obligation to teach and develop self-help skills such as eating, bathing, toileting, dressing, and cleaning, the actual practices at BSDC mirror a "convenience for staff" approach rather than meeting the individual needs of those living at BSDC:⁵⁵
 - For many residents there is no selection of food.
 - Plastic utensils for eating are mandatory.
 - Bibs are tied around residents instead of napkins being available.

⁵³ Medicare and Medicaid regulations require facilities housing and treating residents with developmental disabilities to protect them from harm, to provide adequate staffing, and to protect them from abuse. 42 C.F.R. § 483.420 (a) (5) (requiring that the facility "ensure that clients are not subjected to physical, verbal, sexual or psychological abuse or punishment."); 42 C.F.R. § 483.430 (d) (1) (requiring facilities to provide sufficient direct care staff to manage and supervise residents); 42 C.F.R. § 483.440 (a) (1) specifies the requirements for an active treatment program.

⁵⁴ See, e.g. *Youngberg v. Romeo*, 457 U.S. 307, 322 (1982) (Persons with developmental disabilities residing in State institutions have a constitutional right to "minimally adequate training."). An essential component of habilitative treatment for persons with developmental disabilities is the regular provision of activities designed to help them develop new skills and practice skills already learned. 42 C.F.R. § 483.420 (6) (requiring that facilities "ensure that clients are provided active treatment to reduce dependency on drugs and physical restraints."). See generally, Title XIX of the Social Security Act, 42 U.S.C. § 1396; 42 C.F.R. § 483 Subpart I (Medicaid Program Provisions).

⁵⁵ CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) 223-233; 251-255. The CMS surveyors documented the failure of BSDC to develop programs to address the basic needs of over 20% of residents in sample. *Id.*

- For many, their food is served on Alladin trays from the central kitchen.⁵⁶
- Those that attend the serving line have their food placed on their trays.
- Personal snacks remain locked and unavailable without staff assistance.
- Laundry facilities remain locked.
- Many incontinent residents do not have toileting programs in their Personal Plan Review/Modification Sheet (PPR/MS).⁵⁷
- Their sanitary and hygienic needs remain unmet.

The Center for Medicare and Medicaid Services (CMS) survey report of October 2006 found that the Beatrice State Developmental Center (BSDC) and state officials had departed from federal regulations in **seven out of eight critical areas** (emphasis supplied) that impacted directly on the lives of all residents living at the facility.

Two of those areas are related to the repeated failure of state officials to protect BSDC residents from harm^{xxii} while the remaining five are related to the failure of state officials to provide habilitation that met constitutional standards.

1. **Facility Staffing:** BSDC was found in violation of 42 C.F.R. § 483.430. An asterisk (*) by the finding indicates that CMS identified the violation as having the potential to impact all residents living at BSDC. Specifically:

- State officials failed to ensure sufficient numbers of trained and knowledgeable staff to design and carry out the residents' programs and to ensure the health and safety for residents at the facility.*
- State officials failed to ensure that staff was trained and knowledgeable regarding the necessary training and supports for the residents with whom they work.*
- State officials failed to provide sufficient trained direct care staff to manage and supervise residents with their Individualized Program Plans (IPPs).⁵⁸ *

⁵⁶ In April of 2007, CMS surveyors found that on four of the residences BSDC was not meeting the federal regulations that the facility prepare a palatable, attractive and well-balanced diet. CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-192) 170-173.

⁵⁷ 42 C.F.R. 483.440 (c) (6) (iii) requires that the individual program plan include training for those individuals who lack the personal skills essential for privacy and independence, (including but not limited to toilet training, personal hygiene, dental hygiene, self-feeding, bathing, dressing, grooming, and communication of basic needs) until it has been demonstrated that the client is developmentally incapable of acquiring them. See CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) 223-233; 251-255.

⁵⁸ CMS survey October, 2006. Id. 144-145; 162-168; 168-187. CMS surveyors detailed the devastating consequences that the staff shortages at BSDC have for the individuals living there. Safety and health is jeopardized

- Qualified Mental Retardation Professionals (QMRPs) failed to ensure that residents received necessary service and supports.*
- QMRPs failed to ensure appropriate staff participation in the development of IPPs for the residents they serve.*
- QMRPs failed to ensure that residents were integrated into the community and that active treatment programs were developed, implemented and monitored to assure active habilitation for each person.^{xxiii} *
- Registered dietician and vocational staff failed to attend annual planning meetings for the residents and necessary nutritional assessments went undone.^{xxiv} *
- Residents were denied adequate vocational training to ensure community integration and to ensure overall active treatment.*
- Professional program staff is regularly not available after normal working hours to assist or provide guidance to direct care staff.
- Professional staff (such as vocational specialists and licensed nutritionists) often does not participate in development of program plans for the people living at BSDC.

As a result of a chronic shortage of minimally trained direct care staff coupled with an increasingly greater number of people living at BSDC who require significant behavioral interventions has created a setting in which harm and the risk of harm have risen exponentially.

2. **Active Habilitation:** CMS surveyors also determined that BSDC was in violation of 42 C.F.R. § 483.440 in that state officials failed to provide a program of consistent, continuous, and aggressive training for residents at the facility that potentially affected all BSDC residents. State officials did not and cannot meet the very justification for the continued confinement of individuals at BSDC.^{xxv} Specifically, CMS surveyors found that state officials had failed to:

daily and programs so necessary for habilitation exist either only on paper or are run occasionally and haphazardly. Id. 168-187; 188-215.

- ensure the participation of professionals in the development of individualized plans for residents, impacting on nutritional and health needs;
- ensure that residents attend quarterly mental health treatment program reviews or interdisciplinary team meetings;
- ensure that the Individual Program Plans (IPPs) truly reflect the individual needs of the residents;
- complete functional analyses of maladaptive behaviors to ascertain the causes of aggressive or self-injurious behaviors ; and
- assess restrictions or monitor restrictions on client’s freedom of movement within the institution, access to personal items, food, snacks, cleaning, and medications.^{xxvi}

3. **Behavior Management:** One consequence of the failure to provide active treatment is that the maladaptive behaviors of the residents escalate, creating a downward spiral into greater chaos and violence within the facility. This downward spiral is evidenced by the unfettered growth of institutional deficiencies and failures to meet accepted professional standards of care in violation of the federal regulations, as documented in the CMS surveys of the facility from 2001 through 2007.⁵⁹ CMS found BSDC to be in violation of 42 C.F.R. § 483.450 in that state officials failed to ensure that techniques to manage inappropriate behaviors by residents were an integral part of their individual program plans and were employed with sufficient safeguards to prevent injury to clients. This systemic failure by state officials had an impact on all residents at the facility.^{xxvii}

⁵⁹ In assessing whether a departure from accepted professional standards of care has occurred, it is appropriate to look to the opinions of experts and, where available, national standards and applicable regulations. Thus, accepted professional standards of care may be found by considering the regulatory standards or requirements such as those found in 42 C.F.R. § 483 Subpart I (Medicaid Program Provisions). Consequently, BSDC’s continued failure to meet those standards and be forced to continually develop plans of compliance which later are not fulfilled raises a *prima facie* case of a substantial departure from accepted professional standards of care under the *Youngberg v. Romeo* supra, decision.

In addition, CMS surveyors found that state officials did not have policies and practices in place to:

- identify the use of restrictive interventions from the least intrusive to the most intrusive^{xxviii} *;
- ensure that physical and mechanical restraints were used with sufficient safeguards so as to prevent injuries to clients. **This egregious failure resulted in a finding of immediate jeopardy**^{xxix} *;
- ensure that the use of physical and mechanical restraints and drugs were an integral part of the resident's IPP and intended to lead to less restrictive means of managing behaviors; and
- develop plans to reduce dependence on behavior controlling drugs for significant numbers of residents.^{xxx}

Specifically, NAS finds that:

- Crucial behavior management plans (BMPs) are:
 - delayed in development
 - often not followed by direct care staff
 - inappropriately altered by the practice on the living unit, and
 - neither reviewed nor modified when interventions have not been successful.^{xxxi}
- Functional analysis of maladaptive behaviors is not contained in treatment plans to ascertain causes of aggressive or self-injurious behaviors.^{xxxii}
- Mechanical restraints are regularly and excessively employed against residents with BMPs in contravention of both the BMP and the IPP (Individual Program Plan).
- The facility fails to ensure that restrictive interventions are not used for convenience of the staff.
- Staff is inadequately trained in Mandt techniques to ensure appropriate use of the physical and mechanical restraints so as to protect the individual residents from injury.⁶⁰

⁶⁰ 42 C.F.R. § 483.420 (a) (5) requires the facility to ensure that residents are not subjected to physical, verbal, sexual or psychological abuse or punishment. The CMS most recent investigations in 2006 and 2007 have conclusively and unequivocally found that individuals at BSDC have been repeatedly subjected to physical, verbal and sexual abuse. See CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) pgs 89-103; Staff are uncertain as to time durations of Mandt holds. Id. 182, pgs. 106-145; CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-198) pgs 25-31; 59-105.

Consequently, the facility was found to regularly use restrictive measures as a convenience for the staff^{xxxiii}.

4. **Medical Services:** BSDC was also found to be in violation of 42 C.F.R. § 483.460 in the ability to provide basic medical, nursing and dental services to the residents who live at the facility. Specifically, state officials failed to:

- provide an emergency level of care beyond the ability of the out-patient clinic;
- provide an annual comprehensive dental examination for some of the residents;
- medically examine residents after allegations of rape or sexual assault pursuant to accepted medical protocols;
- instruct residents in skills leading to self-administration of medications; and
- implement a system to actively prevent possible infection from communicable diseases.^{xxxiv}

5. **Nutritional and Dietary Needs:** CMS surveyors also found that BSDC was in violation of 42 CFR § 483.480 in that state officials had failed to:

- consistently follow the physician ordered therapeutic dietary plans;^{xxxv}
- consistently provide therapeutic diets to meet each resident's nutritional needs;
- serve food to residents at appropriate temperatures within a reasonable time period;
- ensure each resident received food liquids that were at the consistency that each resident needed and only to the extent required;
- provide residents with adaptive eating equipment and train residents on the use of adaptive eating equipment;
- teach residents commensurate with their functional level eating skills; and
- provide residents an opportunity to participate in family style dining.^{xxxvi}

During surveys conducted in April of 2007, CMS surveyors found, as they had six months earlier, that BSDC again failed to meet the requirement of § 1905 (d) of the Social Security Act and substantially departed from the accepted professional standards of care established in federal regulations for intermediate care facilities for the mentally retarded (ICFs/MR). Even though state officials had submitted and CMS had approved a Plan of Correction, the current conditions at BSDC were found to violate federal regulations necessary to meet the constitutional obligations of state officials to provide habilitation to the residents living at BSDC.^{xxxvii}

BSDC was found to be in violation of 42 C.F.R. § 483.440, in that state officials again had failed to:

- provide a program of consistent, continuous, and aggressive training for residents at the facility;
- meet the very justification for the continued confinement of citizens at BSDC;^{xxxviii}
- ensure that each resident received necessary assessments, program development, and program implementation^{xxxix} from staff knowledgeable to provide support and services to each resident;^{xl}
- provide residents formalized training in money management, vocational services and self-help or basic personal cares and skills which impeded any opportunity for BSDC residents to transition to a less-restrictive community program;^{xli}
- assess the need to restrict residents' access to items in their living units based on a functional analysis of resident behavior, including the need for refrigerators to remain locked on living units;^{xlii} and
- develop Individual Program Plans (IPPs) that contained program objectives to meet the needs of the residents.^{xliii}

In fact, CMS found that staff was allegedly documenting programs as being followed while the individual residents claimed to be participating were observed sleeping by CMS surveyors.^{xliv}

As they had six months earlier, CMS surveyors in April 2007 documented continued deficiencies in the medical and dietary care of BSDC residents including the failure to: provide needed dental services; train residents in self-medication; prepare and serve palatable and well-balanced meals; and consistently provide the therapeutic diets as planned.^{xlv}

A majority of residents at BSDC have a history of exhibiting challenging behaviors, such as aggression and self-injury.⁶¹ The CMS survey reports of BSDC for October 2006 and April 2007 clearly document that ineffective behavior management programs (BMPs) for residents at the facility have led to an increase in the use of restraints and injuries to the residents.^{xlvi} NAS finds the BMPs for a significant number of people residing at the facility failed to:

- use positive reinforcement and are detrimental because they depart substantially from accepted professional standards of care;
- inform staff how relevant medical, medication, and psychiatric conditions affect the resident; and
- provide specific times and manners for professional and interdisciplinary team review, assessment and modification.^{xlvii}

This departure from generally accepted professional standards by state officials in the development, implementation, monitoring, assessment, and review of BMPs was most evident at the following four living units at BSDC: 104 Kennedy⁶², 108 Kennedy, 402 State, and 406 State.⁶³ Moreover, the shortage of five psychologists at BSDC since

⁶¹Nearly fifty percent (50%) of the individuals at BSDC are receiving medications to control injurious behaviors to themselves or others and over forty percent (40%) have significant behavioral needs requiring behavior program intervention.

⁶² CMS surveyors reported that state officials at BSDC recently split 104 Kennedy into two separate units (102 and 104 Kennedy) in an attempt to deal with the significant problems and failures existing at 104 Kennedy. See BSDC Administrative Review of 104 Kennedy (Individual, Home or Day Environment) August 24, 2007.

⁶³ This conclusion is derived from a detailed review of individual incident reports at the Kennedy residential units by NAS and the NAS Chart of Incidents of Abuse/Neglect From January 2007-August 2007 (hereinafter NAS Chart) which depicts in spreadsheet fashion the monthly occurrence by living residence of the different types of

December of 2006 has had a drastic impact on the facility's ability to meet the habilitation needs of the residents who need BMPs.⁶⁴

CMS surveyors found that state officials failed to develop BMPs that meet accepted professional standards of care. Specifically, state officials had again failed to:

- implement adequate and appropriate BMPs consistently and correctly for residents so as to meet minimum constitutional standards of habilitation;
- develop behavioral programs that adequately meet the needs of residents in a reasonable amount of time;^{xlviii}
- provide sufficient numbers of appropriately trained staff to consistently implement the behavior plans;⁶⁵ and
- provide staff with adequate competency-based training to correctly and properly implement behavior programs.

As a result, citizens at BSDC are at continued risk of harm by not receiving treatment or habilitation that meets accepted standards of professional care.⁶⁶ Many BSDC staff members fail to demonstrate the level of competency necessary for making implementation efforts meaningful and effective.^{xlix} The chronic and persistent shortage of trained staff continues to make implementation efforts problematic at best and futile at worst for state officials working to address the problems at BSDC.

Abuse/Neglect/Death incidents for the period of time January 2007 through August of 2007 based on monthly statements of investigations, incident reports and the BSDC Client Abuse, Neglect and Exploitation Log for 2007.

⁶⁴ Statement of BSDC Head of Psychological Services on September 28, 2007 when explaining that a client of NAS with significant behavioral needs after six months still did not have the necessary BMPs developed and written.

⁶⁵ See: **(Incident #054)** and **(Incident #019)** for examples of BMPs not being implemented.

⁶⁶ The lack of functional analysis by state officials for the behaviors of residents at BSDC leads to poor outcomes for those individuals. A "functional analysis" is a professional assessment technique that relies on a detailed analysis of a person's behavior. The main purpose of a functional analysis is to identify which event(s) or antecedent(s) prompt certain behaviors. By obtaining a greater understanding of the causes of challenging behaviors, professionals can attempt to reduce or eliminate these causal factors, and thus reduce or eliminate the challenging behaviors. Without an informed understanding of the cause of behaviors, attempted treatments are arbitrary and, typically, ineffective. For examples see: **(Incident #028)**; **(Incident #029)**; CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) 300-314.

FINDING III

Nebraska Advocacy Services Finds That State Officials Have Deprived Citizens Living At the Beatrice State Developmental Center Of Receiving Services in the Most Integrated Setting and Failed To Pursue the Timely Transition of Residents into the Most Appropriate, Integrated Settings As Required By the Americans with Disabilities Act

Nebraska Advocacy Services (NAS) further finds that the state officials have failed to provide services to a significant number of people living at the Beatrice State Developmental Center (BSDC) in the most integrated setting, as required by the Americans with Disabilities Act (ADA).⁶⁷ Specifically, we find that in those residential living units at BSDC that attempt to model family homes (cottages):

- the kitchen areas of each “home” have not been modified to accommodate either preparation of all hot foods or the physical limitations of people who live in the “home”, e.g. kitchen sink and counter areas have not been made adaptable for use by residents who use wheelchairs;
- do not provide serving utensils normally found in homes where “family style” meals are served;
- do not have range tops on which residents can learn to prepare food in saucepans and learn safety practices when working with hot surfaces.¹

Additionally, federal law requires that state officials actively pursue the timely transition of people residing at BSDC into the most integrated and appropriate setting that is consistent with the residents’ needs and not opposed by the individual. We find that this is not the case at BSDC:

- The facility fails to provide adequate training and habilitation to prepare a significant number of residents currently living at BSDC for transition to integrated services.⁶⁸

⁶⁷ U.S.C. § 12132 *et seq.*, 28 C.F.R. § 35.130 (d); see also *Olmstead v. L.C.*, 527 U.S. 581 (1999).

⁶⁸ See: Executive Order 13217 “Community-Based Alternatives for Individuals with Disabilities” (June 18, 2001). President George W. Bush in Executive Order 13217 emphasized that unjustified isolation or segregation of qualified individuals with disabilities in institutions is a form of prohibited discrimination, that the United States is committed to community-based alternatives for individuals with disabilities, and that the United States seeks to ensure that America’s community-based programs effectively foster independence and participation in the community for

- Habilitation programming that does occur at the facility is designed to adjust the resident to long-term life at the institution.
- School-age residents at BSDC are not educated in community schools operated by the Beatrice School District, but remain in segregated settings on the grounds of the facility.

State officials have failed to achieve a more inclusive and integrative education for those residents who are school-age. Consequently, segregation, not integration, remains the educational policy of state officials toward school-age residents at BSDC.⁶⁹

CONCLUSIONS

Nebraska Advocacy Services, Inc. (NAS) concludes that state officials have departed and continue to depart from generally accepted professional standards at the Beatrice State Developmental Center (BSDC). The examples we have identified as a result of our ongoing investigation supplements the findings contained in the Center for Medicare and Medicaid Services (CMS) survey reports from Fall 2006 and Spring 2007. The direct and immediate result of the long-term pattern and practice on the part of Nebraska's state officials has resulted in a significant departure from generally accepted professional standards and the continuing denial of the constitutional and statutory rights of residents living at BSDC to reasonable safety, adequate habilitation to ensure physical

Americans with disabilities. 66 Fed. Reg. 33155 (June 18, 2001). The executive order directed the Attorney General to fully enforce Title II of the ADA, especially for those that languish unnecessarily so in facilities like BSDC.

⁶⁹ CMS surveyors detail the failings of the school at BSDC in their findings concerning the rape of an 18 year old female who reported on 9/14/06 that she was raped in the reading room at the BSDC segregated school by a male 18 year old student whom BSDC knew had a history of violence and sexual predation. CMS surveyors reported, "There seems to be a consensus that supervision of clients in the school area is very minimal and in many instances no specific assignments are made during the school activities...Reports are that several complaints have been made about the situation, but there is no evidence that the issue has been effectively addressed." CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) 91-94.

safety, freedom from physical injury, freedom from unreasonable restraint, prevention of regression, and assistance in the exercise of protected liberty interests.⁷⁰

NAS further concludes that the historical narrative of BSDC reveals that state officials continue to fail in the primary objective of the habilitation of residents with developmental disabilities due to identified and documented conditions that have been well-known and existent for years. Specifically, state officials operate a facility which remains overcrowded. The effects of such overcrowding are compounded especially in light of the growing complexity of the needs of the residents living and entering the facility. The increased complexity of resident's needs, when coupled with the persistent failure to recruit, maintain, and appropriately train sufficient numbers of direct care staff and highly motivated professional staff, creates a vicious cycle. Consequently, state officials at BSDC continue unsuccessfully to even meet the basic sanitary and hygienic needs, as well as failing to prevent the continuation of injuries, and physical and sexual assaults, of residents at the facility under their care and treatment.

We further conclude that the federally mandated requirements of professionally accepted standards for the treatment and habilitation of the residents at BSDC cannot be met by state officials unless significant changes are implemented. The growing complexity of the needs of the citizens at BSDC require sophisticated, effective, data-driven behavioral plans and individual program plans which are promptly and properly prepared based upon adequate functional analyses, implemented by adequately trained

⁷⁰ At BSDC there have been **220** internal investigations of abuse and neglect since January 1, 2007, resulting in **86** substantiated cases of abuse and neglect; **22** fractures since January; **209** staff suspensions; **2** Team Leaders with 2 substantiated cases of abuse/neglect; **12** Direct Care staff with 2 or more cases of substantiated abuse/neglect and **1** Direct Care staff person with 4 substantiated cases of abuse/neglect. Furthermore, there have been 10 bone fractures suffered by persons who are non-verbal. Some of those have included a broken finger, broken fibula, fractured right knee, fracture of surgical neck of left humerus and humeral head, spiral fracture of the left distal tibia and the left proximal fibula, fractured left fibula with displacement, fractured right humerus and fractured left foot. *Statistics at BSDC* a report prepared by NAS, October 2007; *Analysis of Fractures with Unknown Causes for Individuals (Non-verbal)* a report prepared by NAS, October 2007.

staff, and monitored and reviewed during implementation for necessary modifications. NAS suggests that the geographical location of the facility, segregated and isolated both physically and symbolically from the treatment community and its professional support and assistance, (1) contributes to the continuation of state officials' failure to employ, train, and then maintain sufficient numbers of highly motivated and well-trained direct care and professional staff essential to habilitate the citizens at BSDC with their demanding complex needs and (2) guarantees the perpetuation of the historical failures at the facility.

NAS concludes that the conditions and practices at BSDC that violate the constitutional rights of the residents living there historically continue to manifest themselves, despite relatively brief and fleeting efforts of remedial reform efforts, and remain imbedded at BSDC. Due to the systemic nature of these conditions and practices at BSDC, the meaningful protection and habilitation of the vulnerable residents living at BSDC requires the enactment and implementation of fundamental changes by the executive and legislative branches of the State of Nebraska to effectuate a meaningful, substantial and lasting resolution. We believe that the evidence contained within the pages of the historical record of BSDC, from its inception in 1885 to the present, establishes that identical problems and failures have manifested themselves throughout the respective periods of the institution's history. To ignore that history is to allow those problems and failures to linger for future generations of vulnerable Nebraskans to endure.

We conclude that state officials must reduce the current population at BSDC, by placement into appropriate community-based settings, to a level consistent with an acknowledgment of the historical reality of the difficulty of maintaining sufficient

numbers of staff. This reduction in the population at BSDC must be accompanied by enhanced financial compensation of professional and direct care staff in order to attract and maintain staff that who are both highly qualified and motivated to meet the habilitation needs of those people who continue to live at BSDC. In addition, state officials must establish an organizational culture at BSDC that is based on an understanding of the historical and social dimensions of the devaluation of people with developmental disabilities.⁷¹ Innovative model programs based upon the principles of consistent positive reinforcement also must be developed and implemented as part of the on-going habilitation of those residents at BSDC with significant behavioral impairments.⁷²

NAS also concludes that state officials should develop and implement a meaningful plan to meet and fulfill the “integrative” mandates of federal law, as required by the Americans with Disabilities Act (ADA) and the decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999).⁷³ The plan must ensure that all school-age children currently living at BSDC receive a “free and appropriate public education” within the schools of the Beatrice School District. State officials in the Department of Health and Human Services and the Nebraska Department of Education must ensure an inclusive and integrative education and eliminate the current *de jure* and *de facto* educational segregation at BSDC. In order to fulfill the integrative mandates of federal law state officials and other interested parties must undertake a re-conceptualization of the current role and function

⁷¹ One possible approach worthy of consideration is Social Role Valorization (SRV) training. SRV is “The application of empirical knowledge to the shaping of the current or potential social roles of a party (i.e., person, group, or class)—primarily by means of enhancement of the party’s competencies & image—so that these are, as much as possible, positively valued in the eyes of the perceivers.” Wolfensberger, W. & Thomas, *Introductory Social Role Valorization workshop training package*, Training Institute for Human Service Planning, Leadership and Change Agency Syracuse University: Syracuse, New York (2005).

⁷² See, for example, McGee, J & Brown, *A Gentle Teaching Primer* (Michigan: Gentle Teaching International 2007); see also www.gentleteaching.com

⁷³ See fnnts 66 and 67 supra.

of BSDC along the lines envisioned by state planners in 1985 of supporting and not supplanting community treatment and services for residents with developmental disabilities. State officials should formulate, develop and implement a truly integrative unitary system of services for Nebraska's citizens with developmental disabilities instead of merely continuing the pattern and futile practice of piecemeal patching the ever-deepening cracks in the dual system of institutional and community-based services. Otherwise, the walls of BSDC which have been eroded over time by stagnation and complacency will continue to crumble around the very citizens they were designed to protect and treat.

Finally, we conclude that the Nebraska Legislature must establish a BSDC Oversight Commission comprised of Nebraska's most knowledgeable citizens (private, public and governmental) who are well-versed in both the short-term and long-term habilitation needs of individuals with developmental disabilities, understand the challenges they and their families face, and are informed of new developments and approaches in the habilitation of individuals with developmental disabilities. With the objective of weaving a tapestry of a new integrative unitary system this Commission can provide, as did the Commission in 1968⁷⁴, the recommendations for not only an impetus for true reform but a renaissance of the innovative vision that made Nebraska the pathfinder in the nation and the world in services for individuals with developmental disabilities during the 1970s and early 1980s.⁷⁵

⁷⁴ The Citizens' Study Committee on Mental Retardation rested on foundational principles that are instructive for any future task force: (1) principles of social role valorization, (2) integrative models with inclusion in the community maximizing family contact, (3) protection of human, legal, and social rights, (4) necessary personal and citizen advocacy. See *Into the Light*, *supra* p. 5; *Out of the Darkness*, *supra* at 10.

⁷⁵ *Id.* at 7-52; 138-153; 156-202.

At best, state officials have continued the pattern of the past six years of applying a Band-Aid to a laceration of the carotid artery at BSDC by promising compliance with the mandated constitutional and federal standards, and yet repeatedly failing to meet the accepted professional standards of care because they have never resolved the historically recurrent problems that we have identified. We conclude that only an innovative approach that incorporates solutions addressing all aspects of the long-term, lingering problems previously identified and so often documented at BSDC will succeed.

RECOMMENDATIONS

1. State officials should conduct independent comprehensive evaluations and objective assessments of all individuals at the Beatrice State Developmental Center (BSDC) and prepare a plan with timelines to significantly reduce, by placement into appropriate community settings, the current population to a level consistent with the historical reality of the difficulty of maintaining sufficient numbers of adequately trained and highly motivated staff to meet the habilitation needs of the people living at the facility.
2. State officials should create and utilize effective, data-driven behavioral plans and individual program plans which are promptly and properly prepared based on adequate functional analysis, implemented by appropriately trained staff and monitored and reviewed during implementation for necessary modifications.
3. State officials should provide BSDC staff with adequate competency-based training to properly implement behavior programs and require demonstration of competency in order to make implementation efforts meaningful and effective for the residents.
4. BSDC should develop and implement individualized programs using the principles of consistent, positive reinforcement, such as “Gentle Teaching” to assist in the habilitation of residents at BSDC who have significant behavioral impairments.
5. State officials should establish an organizational culture at BSDC that is based on respect for and valuing of people with developmental disabilities.
6. All state officials, direct care staff, professional staffing, and medical staff at BSDC should participate in Value-Based Training, such as Social Role Valorization (SRV), to increase their competencies in appreciating the respect and value of people with developmental disabilities.
7. State officials should develop and implement a meaningful plan to meet and fulfill the “integrative” mandates of federal law, as required by the Americans with Disabilities Act (ADA) and the decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) for individuals living at BSDC.
8. State officials should develop and implement policies and procedures to ensure that all school-age children currently living at BSDC receive a “free and appropriate public education” within the facilities operated by the Beatrice School District by the Fall of 2008.

9. State officials should substantially increase levels of compensation and benefit packages for direct care and professional staff at BSDC in order to attract and maintain highly qualified and motivated staff necessary for the habilitation of those residents who continue to live at BSDC.
10. State officials should create, adequately staff, and fund a Section of Civil Rights Enforcement within the Department of Health and Human Services responsible for the protection, investigation and enforcement of the civil rights of persons residing within the State of Nebraska's residential facilities. The Section of Civil Rights should be comprised of individuals with special knowledge and expertise in the law, federal regulations, developmental disabilities, and behavioral health. The Section of Civil Rights should assist state officials in ensuring that residents at BSDC and the other residential facilities are protected from harm, receive appropriate treatment and habilitation, and that the facilities actually meet those standards of generally accepted care by professionals contained within the federal regulations. The Section of Civil Rights would report directly to the Governor's Office and to the Health and Human Services Committee of the Legislature on a periodic basis. The Governor would have the authority to appoint the Section Head subject to confirmation by the Legislature, and the Section Head could be removed only upon a showing of good cause.
11. The Nebraska Legislature should appoint an Oversight Commission that is comprised of Nebraska's most knowledgeable citizens in the private, public and governmental sectors. Such individuals must be knowledgeable of the habilitation needs of people with developmental disabilities and the challenges they and their families face. The Commission should include persons with developmental disabilities, parents and relatives of persons with developmental disabilities, representatives of advocacy groups, professionals and providers, state legislators, and members of the Executive Branch of the State of Nebraska. The Commission should be charged with issuing recommendations to achieve: (1) a unitary integrative system of habilitation services and supports for individuals with developmental disabilities in Nebraska, and (2) the permanent elimination of the deficiencies at the Beatrice State Developmental Center that have historically persisted at the facility.

ENDNOTES

ⁱ CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 10-26-2001) pgs 1-35.

ⁱⁱ CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-17-2003) pgs 1-13.

ⁱⁱⁱ CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 10-09-2003) pgs 1-6 of 54.

^{iv} CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 01-22-2004) pgs 1-24.

^v CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 03-17-2004) pgs 1-8.

^{vi} CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 03-29-2004) pgs 1-3.

^{vii} CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 10-04-2004) pgs 1-8.

^{viii} CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 05-11-2005) pgs 1-14.

^{ix} Id., 10-14.

^x CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 08-30-2005) pgs 1-7.

^{xi} See generally CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) and CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-192).

^{xii} CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) 1-7.

^{xiii} Id. 8-9.

^{xiv} Id. 9-32.

^{xv} Id. 2-3.

^{xvi} Id., 10-11.

^{xvii} CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-192) 31-34; 62-98.

^{xviii} Id. 35-53.

^{xix} Id. 2-3.

^{xx} Id. CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-192); 26-31.

^{xxi} See fnmt 43, *supra*.

^{xxii} CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413), 35-37.

^{xxiii} Id., 144-159.

^{xxiv} Id., 159-161.

^{xxv} Id., 188-214.

^{xxvi} Id., 223-300.

^{xxvii} Id., 300.

^{xxviii} Id., 301-303.

^{xxix} Id., 301; 303-314.

^{xxx} Id., 301-302; 315-327.

^{xxxi} Id., 300-327.

^{xxxii} Id., 223-224; 300-327.

^{xxxiii} Id., 314-315.

^{xxxiv} Id., 327-385.

^{xxxv} Id., 385-413

^{xxxvi} Id., 385-413.

^{xxxvii} CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-192).

^{xxxviii} Id., 98-141.

^{xxxix} Id., 125-138.

^{xl} Id. 99-102.

^{xli} Id. 99-107; 107-115.120-125.

^{xlii} Id.,107-109.

^{xliii} Id., 115-125.

^{xliv} Id., 135.

^{xlv} Id., 141-192.

^{xlvi} CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 09-29-2006) (1-413) 300-314.

^{xlvii} Id.

^{xlviii} Id.

^{xlix} 42 C.F.R. § 483.430 (e).

^l CMS Statement of Deficiencies and Plan of Correction for the Beatrice State Developmental Center (Survey Completed 04-20-2007) (1-198) pgs 3-5.

Beatrice State Developmental Center: Survey Chart and History of Non-Compliance since September, 2006.



Survey Dates	Surveyors	Survey Type	Results	Immediate Jeopardy (IJ)	Conditions of Participation (CoP) Not Met
9/18/06 – 9/29/06	CMS	Full Survey ✗	3 IJs 7 (of a possible 8) CoPs	2 IJs in Client Protections -Neglect of client who was raped - surveyor intervention required to initiate adequate safeguards. -Abuse system failed to protect all clients. 1 IJ in Client Behavior/Facility Practices -Numerous client injuries during restraint.	-Governing Body and Management -Client Protections -Facility Staffing -Active Treatment Services -Client Behavior and Facility Practices -Health Care Services -Dietetic Services
10/17/06 – 10/18/06	CMS	IJ Follow-Up	3 IJs removed, (7 CoPs)		-Governing Body and Management -Client Protections -Facility Staffing -Active Treatment Services -Client Behavior and Facility Practices -Health Care Services -Dietetic Services
4/10/07 – 4/20/07	CMS	1 st Follow-Up	1 IJ 2 CoPs	IJ in Client Protections -Failure to adequately address and protect clients abused by other clients.	-Governing Body and Management -Client Protections
5/9/07 – 5/11/07	CMS	IJ Follow-Up	IJ removed (2 CoPs)		-Governing Body and Management -Client Protections
10/30/07 – 11/7/07 <i>(This survey is the subject of litigation.)</i>	CMS	2 nd Follow-Up	1 IJ 4 CoPs	IJ in Client Protections -Maintained employment of staff members after they had physically abused clients. <i>(IJ removed during survey)</i>	-Governing Body and Management -Client Protections -Facility Staffing -Active Treatment Services
2/25/08 – 3/4/08	CMS / State Agency (SA)	3 rd Follow-Up	3 IJs 5 CoPs	2 IJs in Client Protections -Abuse system failed to protect all clients -Failure to protect client from self abuse. 1 IJ in Physical Environment -Inadequate emergency evacuation system for clients who use wheelchairs.	-Governing Body and Management -Client Protections -Facility Staffing -Active Treatment Services -Physical Environment
3/6/08	CMS / SA	IJ Follow-Up	3 IJs removed 1 CoP Met (4 CoPs)	<i>(Removal of the IJ at Physical Environment was sufficient to find the CoP of Physical Environment met, as well.)</i>	-Governing Body and Management * -Client Protections * -Facility Staffing * -Active Treatment Services *
3/21/08 – 3/27/08	SA	Incident Investigation	1 IJ 3 CoPs	IJ in Client Protections -Failure of 3 staff to initiate CPR resulting in a client death; found 114 staff not trained in CPR	-Governing Body and Management -Client Protections -Health Care Services
4/30/08 – 5/1/08	SA	IJ Follow-Up	IJ removed (3 CoPs) *		-Governing Body and Management -Client Protections -Health Care Services *

*Currently there are 5 CoPs Not Met -four (4) as a result of the 3rd Follow-Up survey and one (1) as a result of the SA Incident Investigation.



State of Nebraska

Dave Heineman, Governor

October 8, 2008

Ms. Nadine Renbarger, MA/QMRP
 Technical Advisor
 Centers for Medicare & Medicaid Services
 233 North Michigan Avenue, Suite 600
 Chicago, Illinois 60601-6519

RE: Beatrice State Developmental Center (BSDC) Settlement Discussions

Dear Ms. Renbarger:

Thank you for meeting with us and giving the Nebraska Department of Health & Human Services the opportunity to provide you with requested information and move positively forward concerning the settlement of Medicaid certification for the Beatrice State Developmental Center. These responses, along with the verbal information provided by Ron Stegemann, CEO, during our recent meeting at the Kansas City office of CMS, outline enhancements made for client services related to conditions and standards within Title XIX.

1) Staffing numbers comparison for March & September 2008 for both permanent, temporary and contract positions:

Staffing numbers as of March 1, 2008 and September 29, 2008, are included in Exhibit 1. Exhibit 1 includes individuals who are classified as employees by Full Time Equivalency (FTE). Exhibit 1 also includes positions which are being filled by long-term contracts with individuals.

2) The following are new staff since March 1, 2009 (positions filled by contracts are indicated with an asterisk):

a) To enhance on site services and accountability at each home, and the supervision, training, coaching and morale of direct care employees:

- i) One Orientation Facilitator (Personnel Officer) – to work on staff retention, especially that of new hires during their first six months of employment to build working relationships and find solutions to work-related problems which might affect their ability and willingness to remain employed by BSDC. Status: filled.
- ii) Four Mentor (Developmental Technician III) positions – to serve as coach/mentor to newly hired Developmental Technicians and work alongside the new hires to teach fundamental developmental care services, habilitation training and recreational activities related to the

needs of developmentally disabled individuals at BSDC. Status: Anticipated start date of 11/14/08.

- iii) Sixty-Six Developmental Technician Shift Supervisors – to serve within Neighborhood Services, providing direct supervision, support, coaching and mentoring to Developmental Technicians 1, 2, and 3 at the service delivery level; participate in hiring and in recommending and issuing disciplinary actions for work performance issues; provide on-the-job training and regular performance feedback and evaluation. Status: currently recruiting.

b) To enhance active treatment and direct services at BSDC:

- i) Two Recreation Activity Specialists (Community Integration Specialist) – to provide recreation support and implementation and leadership of recreational activities based on community integration; collaborate with interdisciplinary teams to determine assessed needs and preferences; develop community integration opportunities; promote social capital in the community setting, and provide in-service to staff. Status: filled.
- ii) Two Recreation Aides – to provide recreation supports and to conduct general recreation activities, music activities, lifeguarding services, assist with special events and transport individuals. Status: filled.
- iii) Three Vocational Activity Specialists – to conduct vocational assessments; evaluate level of functioning to reflect social needs, abilities, and interest for placement in activity therapy programs; assist with evaluating jobs for employment training; assist with teaching clients to perform jobs; participate in treatment team meetings; assist in developing instructional task analysis for each job to provide effective training strategies; record and analyze data. Status: 1 filled, 2 actively recruiting.
- iv) Speech Pathology*- to assist with coverage while recruiting to fill existing positions and to supplement existing positions long-term, contracts have been entered into with Kari Daniels, MS, CCC-SLP, and Shari DeVaney, MS, CCC-SLP, to provide speech evaluation and limited therapy services; recruitment of additional part-time staff is also ongoing.
- v) Physical Therapy*- to assist with coverage while recruiting to fill existing positions and to supplement existing positions long-term, the facility has contracted with Ruth Huston, PT, retained to provide physical therapy services to meet client needs; in addition to a verbal commitment from Paul Potter, PT, for physical therapy services to meet client needs, further recruiting is ongoing.
- vi) Psychology*- to assist with coverage while recruiting to fill existing positions and to supplement existing positions long-term, BSDC has

contracted for psychology services through Dr. Lee Zlomke, Ph.D., and Pediatric Psychological Associates to provide behavioral functional assessments, creation of Behavioral Support Programs, and to perform administrative functions, and with Dr. Rod Koch to provide supervision for provisionally licensed psychology staff.

- vi) Neighborhood Services Administrator* - to provide supervision and leadership for the Neighborhood Services division, which includes three Area Administrators and in direct supervision to the QMRPs, Home Managers, HSTS and Direct Care Staff. Incumbent is responsible for allocation of staffing resources to maintain safety and active treatment. BSDC has contracted through Guardian Healthcare Providers Inc. for the services of Dan Hyman, who began serving as Neighborhood Services Administrator on September 22, 2008. He brings expertise in management, resident care, employee development and compliance with government regulations to this new position. Since 2002, he has served as Program Services Director of Hillsborough County Developmental Center in Tampa, Florida, an intermediate care facility that serves 64 people. Previous positions include serving as acting director of residential services at the Richland County Board of Mental Retardation/Developmental Disabilities in Mansfield, Ohio and as assistant superintendent of Broadview Developmental Center in Broadview, Ohio. Dan has a bachelor's degree in education and a Master of Education degree from the University of Toledo in Toledo, Ohio.

- viii) QI Director* - to provide supervision and leadership for the QI Division, which includes four Program Specialists, the Investigations Department and oversight of the BSDC QI Plan. BSDC has contracted with Dr. Virginia Meehan and continues to provide facilitation one week per month for the revised BSDC QI Plan; Angela Server, through contract with Guardian Healthcare Providers Inc., will begin duties as the full time BSDC QI Director on October 13, 2008. She has served as the ICF/MR Director at Graceworks Enhanced Living in Cincinnati, Ohio since July, 2007. Previous experience includes serving as Program Manager at Graceworks Enhance Living, AMRP at Fairfield Center in Fairfield, Ohio, Residential Specialist at Mike An Group in Springdale, Ohio and at the Fairfield Center in Fairfield, Ohio. Angela has a bachelor's degree in special education from Miami University, at US-OH-Oxford.

- ix) Active Treatment Administrator* - to provide leadership and supervision to the department coordinators for Vocational Services, Recreation, Psychology, Therapies and Social Work. The incumbent is responsible for the provision of active treatment for individuals in all environments. BSDC has contracted with Guardian Healthcare Providers Inc., to fill this position; two candidates have completed on-site interviews with one of those candidates rejecting an offer of employment, and the search to fill this position is ongoing.

Delvin Koch, Neighborhood Services Assistant Administrator for Vocational Services, Recreation, Psychology, Social Work, Cosmetology and Religious Services and Alan McVay, Administrator of Nursing for Therapies(PT/OT, SLAS, Dietary) are providing leadership and supervision at the present time.

- x) Investigations Administrator* – to provide leadership and supervision to the lead investigator and indirect supervision to four investigators. Incumbent is responsible to review investigations for thoroughness, timeliness and develop action plans based upon investigation results. BSDC has contracted with Guardian Healthcare Providers Inc., to fill this position, and that search is ongoing.
- xi) Certified Nurse Aides and Supplemental Direct Care Staff* - to provide temporary relief from mandatory overtime during a period in which census was being reduced, homes were being closed, and resources were being allocated, temporary staff from professional staffing agencies were utilized; as we have been able to recruit additional staff and census has been reduced, these temporary staff have been eliminated.

c) To enhance medical services at BSDC:

- i) Medical Director - Dr. Alfred Harrington, M.D. began employment as fulltime BSDC Medical Director on July 21, 2008. He served as President and CEO of Harrington and Associates from 2001 to 2008, focusing on strategic planning and development, community-based education and training, research and program evaluation and health policy analysis and development. Previous experience includes serving as First Vice President and Associate Medical Director at Mutual of Omaha Companies, attending physician at Midwest Minor Medical, and Vice President and Chief Medical Officer at the Charles Drew Health Center in Omaha. He has been a clinical instructor at Omaha's Creighton University, Department of Internal Medicine, since 1992. Dr. Harrington received a bachelor of science degree from Manhattan College, Bronx, New York; Master of Public Health and Doctor of Medicine, Yale University School of Medicine, New Haven, Connecticut; Medical Residency in Internal Medicine and Pediatrics, SUNY Health Science Center at Brooklyn/Kings County Hospital, Brooklyn, New York; Financial Analysis for Physicians and the Program for Manager Development, Certificate Program, University of North Carolina at Chapel Hill, North Carolina; and an Executive MBA, University of Nebraska at Omaha, Omaha, Nebraska.
- ii) One Nurse Practitioner – this position was transferred from a Physician position to that of a Nurse Practitioner. It is being filled by an individual with several years of experience in the field of Developmental Disabilities

and who has both medical and mental health licensing. Status: this position is filled, with a start date of October 27, 2008.

- iii) Neurology* – to expanded neurology services to BSDC residents, we have amended our contract with Dr. George Wolcott to increase his time each week for neurology clinics.
- iv) Psychiatry* - BSDC is currently in negotiations with two psychiatrists to provide for client needs in psychiatry.
- v) One Staff Assistant I (Dental Assistant) – to schedule patients, maintain and file dental records; assist with dental procedures; maintain, clean and sterilize dental equipment; order equipment/supplies; develop x-rays; provide oral hygiene in-service to patients and staff ; and do oral hygiene evaluations on patients. Status: filled.
- vi) Nutritional Management* - to develop, implement and evaluate a BSDC Physical and Nutritional Management Team and program, BSDC has contracted with James Bailey, MCD, CCC-SLP.
- vii) Medical Chart Reviews* - BSDC entered into a temporary contract with a physician and nurse with Liberty Healthcare to provide medical chart review services. BSDC has also contracted with Dr. Daniel Sheridan, Johns Hopkins University to provide medical chart reviews for quality assurance review and planning on an as-needed basis.

3) Current vacant & being recruited positions:

Please refer to Exhibit 4.

4) Staff-to-client ratio comparison of March & September 2008 is as follows:

Shift	March 2008	September 2008
1st	1:3.28	1:2.55
2nd	1:3.35	1:2.73
3rd	1:7.26	1:5.84

5) Voluntary/Mandatory Overtime by Month - Beginning March 1, 2008, to September 28, 2008:

Please refer to Exhibits 5 & 6.

6) Contracts with outside agencies to assist with ICF/MR requirements:

Please refer to the response No. 2 for services and assistance in meeting ICF/MR requirements provided by outside agencies and/or professionals under contract. Contracts are being utilized in the areas of:

- Speech Pathology
- Physical Therapy
- Psychology

- Administration
- Quality Improvement
- Active Treatment (in process)
- Direct Care
- Investigations (in process)
- Neurology
- Psychiatry (in process)
- Nutritional Management
- Medical Chart Reviews

7) Training for QMRPs since March 2008:

Since March, QMRPs, through scheduled Neighborhood Services Area Meetings, have been trained on the following:

- Area Incident Review Team process and procedures
- Emergency Response Drills process and procedures
- Human and Legal Rights Committee review process and informed consent process
- Restraint process, procedures and documentation
- Transition policy and procedures
- Avatar data system log-in and report generation
- Bonita Johnson, retired QMRP with many years experience, provided mentoring to new QMRPs from 02/08 through 06/08.

BSDC is currently finalizing the contract with Michael Smull and Amanda George to resume Person Centered Thinking Training. This will involve Q's, HSTS's and direct care staff in teams. The contract is scheduled to begin in November 2008 and run through June 2009. Training is to include:

- 2-day Person Centered Thinking Training;
- 1-day Coaches Training;
- Half-day training sessions on coaches and leadership;
- Half-day training sessions on coaches support with teams;
- 1-day PCP plan review trainings; and
- Half-day facilitator trainings.

8) Qualifications of the Orientation Facilitator:

This new position is to be a problem-solver and facilitator for new hires during their first 6 months of employment. We hired Ryan Broker into this position late this summer, and he is currently meeting with new hires to build relationships and assist them with problems they might run into.

Ryan has experience at BSDC as an HSTS and music therapist. As such he understands the everyday problems at the facility and can move around the facility fairly easily. Ryan is a proven effective communicator and understands active treatment and the programming mission at the facility. He is also the newly appointed Employee Incentives and Recognition Committee chairperson and has facilitated the implementation of TEAM (Thanking, Encouraging, Acknowledging, Motivating) BSDC.

Ryan is developing job previews for potential job candidates and reviewing exit interview data to improve our recruitment and retention.

The job description for this position calls for knowledge of performance requirements of basic care staff, organizational policy and procedure and facilitation techniques and the ability to solve problems. Ryan was interviewed with these skills and abilities in mind, and he has them and applies them.

9) System changes at BSDC for reporting, responding to, investigating and correcting actions for Abuse and Neglect, along with injuries of unknown origin:

The daily incident review process was de-centralized and is now conducted by the staff at each of the 3 Areas. These reviews are being led by each of the 3 Assistant Administrators with QMRPs, Home Managers, and discipline, QI, and administrative staff in attendance. In addition, an Administrative Incident Review Team was formed with the implementation of the Area Incident Review teams. The Administrative Incident Review Team meets at least every two weeks, and other times as needed, to review a sample of the completed investigations to ensure thoroughness and appropriate safeguards and corrective action plans. The Administrative Review team also reviews summary data for any facility trends of incidents/injuries and creates change and/or assigns actions as needed.

All allegations made by individuals with a history of making false allegations continue to be investigated. Additionally, individual clients continue to receive treatment per any behavior management or habilitation programs.

The facility's Abuse Investigation Review Team continues to review investigations for thoroughness and ensures appropriate corrective actions are taken. Effective April 18, 2008, the membership of the facility's Abuse Investigations Review Team was expanded to include representatives from various facility departments that may have information pertinent to facility investigations. Additional members have included representation by Nursing, safety, and policies. All members of the team received training on investigations prior to serving on the team. Additionally, the CEO reviews recommendations from this group and approves disciplinary and corrective actions prior to the return of all employees to the work force.

Angela Server begins employment as the new QI Director on October 13, 2008. Ms. Server has experience in Quality Assurance planning, and has experience as an ICF/MR Director.

Labor Relations Alternatives (LRA), a nationally recognized company that provides training on investigations, will be providing training to two separate groups of select facility employees the week of November 3, 2008. BSDC staff attending the training will be the facility's new Lead Investigator, new QI Director; two facility Abuse Investigators, and QMRPs and/or Managers that conduct investigations.

Additionally, all Abuse Investigators and other managers/QMRPs that conduct investigations were provided training on investigations this past March/April.

As part of the Department of Justice agreement, notification of allegations of abuse or neglect, serious injuries, deaths, emergency room or hospital admissions, involvement with law enforcement and completed investigative reports of abuse and neglect are reported to Dr. John McGee, Ph.D., Independent Expert. In addition, Dr. McGee receives copies of reports from all completed Administrative Reviews and Critical Incident Reviews. Dr. McGee's resume is attached as Exhibit #8.

The new Investigations Administrator, currently being recruited, will provide expertise with investigation thoroughness, timeliness and completeness, along with development of agency action plans based on investigation results as well as general evaluation of systematic issues and trends associated with protection from harm incidents that are investigated.

10) Breakdown of how contracted services are meeting client needs at BSDC:

These are described in item Nos. 2 and 6 above.

11) Enhancements of the Quality Assurance System at BSDC:

Dr. Virginia Meehan, Ph.D., has facilitated implementation of the new BSDC QI Plan. She will also assist in the transition of the newly hired QI Director.

The BSDC Quality Improvement plan has been expanded to include additional data reporting and analysis. Analysis now includes any references to trends and actions taken by the individual teams in response to the data. The current plan also enables the committee to evaluate comparative data over the past 18 months. Action plans and recommendations are to be developed based on the comparative data.

Additionally, under the guidance of Dr. Meehan, the facility developed QI indicators for each department on campus. The new indicators reflect what each department is to measure to evaluate the client services provided by the respective department. Based on the collection of this data throughout a baseline quarter, thresholds will be established and department heads will have completed drafts of QI plans for their respective department. Data is currently being collected for these newly developed department QI Plans, and will be compiled into the comprehensive facility QI Plan.

The new Quality Assurance System will allow individual departments to track and trend risk factors and the provision of services provided by the department and allow BSDC Leadership to track and trend indicators system-wide based partly on the department indicators and other indicators developed by the QI Committee.

12) Specification of improvements made since March 2008:

a) Abuse and Neglect Prevention:

The Leadership Team recently reviewed that in 2006 there were 226 allegations of employee abuse/neglect investigated, 256 investigated in 2007, and 96 completed through September 16 of 2008.

b) Vocational Services:

- Filled 1 staff position for Community Employment Activity Specialist;
- Currently recruiting for 2 additional Vocational Assessment Activity Specialists;
- Entrepreneurialship developed with 1 individual;
- Currently have 43 individuals employed in the community delivering newspapers;
- Currently have 4 individuals employed in the community in a lawn mowing service;
- Vocational Assessment Activity Specialist have/are attending all requested meetings with the Interdisciplinary Teams; and
- Addition of one contract for packaging of "Flat Lander Lures."

c) Medical Services:

- The hiring of a new medical director;
- The hiring of a full-time psychiatric/Family Practice nurse practitioner;
- The extension of the hours of the BSDC Neurology Clinics;
- Recruitment of psychiatrists to enhance psychiatric services;
- The initiation of transition of BSDC Hospital to BSDC Ambulatory Surgical Center/Public Health Clinic;
- Independent medical chart reviews;
- Initiation of a working relationship between BSDC and BCH to develop optimum care of BSDC patients; and
- Preliminary work on the development of a unified medical record.

d) Community Integration:

Two of the new recreation positions/staff have been building the Community Integration program, including the following efforts:

- Increased visibility in the community through community vocational opportunities such as lawn mowing and paper routes;
- Increased visibility in the community through recreational activities (i.e. bowling, movies, etc.);
- Inclusion of the community in events such as the BSDC Fun Day, Provider Fairs and Catholic Mass;
- Participation by individuals at events such as the Gage County Fair, Nebraska State fair, High School and University plays, concerts and sporting events.
- Establishing relationships and initiating memberships with local organizations such as the YMCA and the Kiwanis Club.
- Developing two small groups who deliver Meals on Wheels to persons in the community each week.

13) Other significant changes at BSDC include the following:

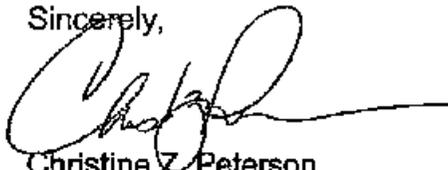
- Since October 2007, the census has been reduced from 332 individuals to 256 individuals;
- Four homes (104 Kennedy, 203, 207 and 307 Sheridan) have closed and resources consolidated to enhance services at other homes, and

consolidation during the next several months will eliminate homes on 2nd floors where individuals who use wheelchairs currently reside;

- Enhanced active treatment services, including focusing on providing activities outside of the homes at least five hours daily;
- Initial implementation of "Life Stories" for individuals at BSDC, specifically piloted for individuals currently transitioning to alternative community service providers;
- Closer coordination between BSDC interdisciplinary teams and Community Based Service Coordination, under the direction of the Developmental Disabilities System since July 1, 2008, to ensure that clients are better informed of community alternatives and to encourage growth of community programs to meet the needs of BSDC clients; and
- Enhanced efforts to improve transitional services to BSDC clients (such as increased visits to community providers); this is to encourage BSDC clients and their guardians to be more fully informed of their options, but has the added benefit of encouraging providers to be more willing to consider provision of services to BSDC clients.
- Paul Kaufmann, DHHS Legal Counsel, has been assigned to work with Developmental Disabilities, BSDC. His resume is attached as Exhibit #9.

In conclusion, this letter, attached spreadsheets and verbal report from Ron Stegemann, CEO, has outlined significant steps taken since March 2008 to promote client protections and in meeting all Title XIX Conditions of Participation. Our continuing dialogue demonstrates our resolve to work in good faith with the Centers for Medicare and Medicaid Services to meet Medicaid certification requirements. We look forward to hearing from you soon to continue toward Settlement Resolution.

Sincerely,



Christine Z. Peterson
Chief Executive Officer
Department of Health and Human Services

CC: Tom York, York Legal Group
Harry Malin, CMS Legal Counsel

Encl.

BEATRICE STATE DEVELOPMENTAL CENTER
Staffing Comparison 3/1/08 – 10/1/08

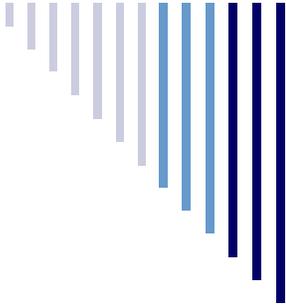
Description	3/1/08	10/1/08				ACTIVELY RECRUITING
	CENSUS: 312	CENSUS: 256				
	FILLED FTE	CURRENT FILLED FTE'S	CURRENTLY FULFILLED BY CONTRACT	FILLED, BUT WAITING FOR START DATE	TOTAL FILLED	
DEVELOPMENTAL TECHNICIAN II ¹	224.00	244.00		7	251.00	27
DEVELOPMENTAL TECHNICIAN III	65.00	63.00			63.00	
DEV TECH MENTORS ²	0.00	0.00			0.00	4
DEV TECH SHIFT SUPERVISOR ³	0.00	0.00			0.00	66
AUDIOLOGIST II	1.00	1.00			1.00	
CERTIFIED MASTER SOCIAL WORKER	5.00	5.00			5.00	
DENTIST	1.00	1.00			1.00	
MEDICAL DIRECTOR	1.00	1.00			1.00	
PSYCHIATRIST	0.00	0.00			0.00	2
MENTAL HEALTH PRACTITIONER II	2.00	2.00			2.00	
NUTRITIONAL MANAGEMENT ⁴	0.00	0.00	1		0.00	
ACTIVE TREATMENT ADMINISTRATOR ⁵	0.00	0.00			0.00	1
NURSE PRACTITIONER ⁶	1.00	1.50		1	2.50	
NURSE SUPERVISOR ⁷	2.00	4.00			4.00	
NURSING DIRECTOR	1.00	1.00			1.00	
NURSING DIRECTOR/ASSOCIATE	2.00	2.00			2.00	
NEUROLOGIST ⁸	0.00	0.00	1		0.00	
OCCUPATIONAL THERAPIST	2.00	2.00			2.00	
PHARMACIST/CLINICAL	3.00	3.00			3.00	
PHARMACY MANAGER	1.00	1.00			1.00	
PHYSICAL THERAPIST II ^{9 & 9a}	2.00	1.00	2		1.00	1

Staffing Comparison 3/1/08 – 10/1/08

Description	3/1/08 CENSUS: 312	10/1/08 CENSUS: 256				ACTIVELY RECRUITING
	FILLED FTE	CURRENT FILLED FTE'S	CURRENTLY FULFILLED BY CONTRACT	FILLED, BUT WAITING FOR START DATE	TOTAL FILLED	
PHYSICAL THERAPY AIDE	5.00	5.00			5.00	
PHYSICAL THERAPY ASSISTANT	1.00	1.00			1.00	
PHYSICAL THERAPY DIRECTOR	1.00	1.00			1.00	
PHYSICIAN ASSISTANT ⁶	0.50	0.00			0.00	
PHYSICIAN	1.00	1.00			1.00	
PSYCHOLOGY DIRECTOR	0.00	0.00	1		0.00	
PSYCHOLOGIST I ¹⁰	1.00	1.00	2		1.00	
PSYCHOLOGIST II	1.00	1.00			1.00	
PSYCHOLOGIST/CLINICAL	3.00	4.00			4.00	2
PSYCHOLOGIST/LICENSED	1.00	1.00			1.00	
QUALITY IMPROVEMENT DIRECTOR ⁵	0.00	0.00	1		0.00	
SOCIAL WORKER II	4.00	3.00			3.00	1
SPEECH PATHOLOGIST II ^{11 & 11a}	2.00	1.00	2		1.00	1
SPEECH/HEARING SERVICES DIR.	1.00	1.00			1.00	
VOCATIONAL REHABILITATION SUPV	1.00	1.00			1.00	
ACCOUNTANT I	1.00	1.00			1.00	
ACCOUNTING CLERK II	2.00	2.00			2.00	
ACTIVITY AIDE	0.00	0.50			0.50	
ACTIVITY MANAGER	1.00	1.00			1.00	
ACTIVITY SPECIALIST ¹²	3.00	8.00			8.00	3
ADMINISTRATIVE ASSISTANT I	2.00	2.00			2.00	
AUTOMOTIVE MECHANIC II	0.50	0.50			0.50	
AUTOMOTIVE/DIESEL MECHANIC	1.00	1.00			1.00	

Staffing Comparison 3/1/08 – 10/1/08

Description	3/1/08	10/1/08				ACTIVELY RECRUITING
	CENSUS: 312	CENSUS: 256				
	FILLED FTE	CURRENT FILLED FTE'S	CURRENTLY FULFILLED BY CONTRACT	FILLED, BUT WAITING FOR START DATE	TOTAL FILLED	
BARBER/BEAUTICIAN SUPERVISOR	1.00	1.00			1.00	
BARBER/BEAUTICIAN	1.00	1.00			1.00	
BUSINESS MANAGER II	1.00	1.00			1.00	
INVESTIGATIONS ADMINISTRATOR ⁵	0.00	0.00			0.00	1
COMPLIANCE SPECIALIST	4.00	4.00			4.00	
CUSTODIAN/HOUSEKEEPER	29.00	29.00			29.00	
DEV DIS PROGRAM MNGR ¹³	3.00	2.00			2.00	
DEVELOPMENTAL SPECIALIST ¹⁴	5.00	6.00			6.00	
DIETITIAN	4.00	4.00			4.00	
DPI PROGRAM MANAGER ¹⁶	0.00	1.00			1.00	
DHHS PROGRAM SPECIALIST ¹⁶	3.00	4.00			4.00	
DUPLICATING TECHNICIAN I	1.00	1.00			1.00	
ELECTRICIAN	2.00	2.00			2.00	
FACILITY MAINTENANCE MGR. II	1.00	1.00			1.00	
FACILITY MAINTENANCE SPEC.	20.00	20.00			20.00	
FACILITY MAINTENANCE SUPV.	3.00	3.00			3.00	
FACILITY OPERATING OFFICER II	1.00	1.00			1.00	
FOOD SERVICE AIDE	2.00	2.00			2.00	
FOOD SERVICE ASSISTANT ¹⁷	18.00	21.00		1	22.00	
FOOD SERVICE COOK ¹⁷	16.50	16.70		1	17.70	
FOOD SERVICE DIRECTOR II	1.00	1.00			1.00	
FOOD SERVICE LEADER	1.00	1.00			1.00	
FOOD SERVICE SUPERVISOR	4.00	4.00			4.00	



Nebraska Legislative Resolution 156

Addressing the Waiting List for Persons
with Developmental Disabilities
and Rate Methodology

December 2008

LR 156 WORKGROUP MEMBERSHIP

The following members of the Legislative Resolution 156 Workgroup are thanked for their hard work and dedication to meet the goals of this project. Membership, as defined in the Resolution, included representatives from the State Department of Education, the Advisory Committee on Developmental Disabilities, the Developmental Disabilities Planning Council, people with developmental disabilities and their families, statewide developmental disability advocacy organizations, developmental disability service providers, and other interested parties. It is the commitment of individuals such as these that leads to positive outcomes for Nebraskans with intellectual and developmental disabilities and their families.

Laurie Ackermann
Janet Anderson
Mary Angus
Bob Brinker
Dennis Byars
June Clapper
Christi Crosby
Glenda Davis
Eric Evans
Rene Ferdinand
Sue Hamilton
Kathy Hoell
Seamus Kelly
Brenda Kimes
Anne Lauritzen

Maxine Lien
Joan Marcus
Carol McClain
Dave Merrill
Marlene Pedulla
Kathy Peterson
Kenneth Rood
Sue Rood
Jack Shepard
Mark Smith
Patty Smith
Carla Sorensen
Tammy Westfall
Alan Zavodny

Special thanks are given to the technical advisors who provided expert guidance and resources to assist in the work of the group.

Mary Gordon, Nebraska Planning Council on Developmental Disabilities
Terri Holman, Nebraska Planning Council on Developmental Disabilities
Don Severance, NDHHS Division of Developmental Disabilities

Project Contractor:
O'Hare Professional Consulting
Mary O'Hare
1205 S. 25th Street
Lincoln NE 68502
maryohare1@alltel.net
402.475.8022

Project Sub-Contractor:
Lloya Fritz
1820 Kings Hwy.
Lincoln NE 68502
lloyafritz@alltel.net
402.730.8469

LR 156 EXECUTIVE SUMMARY

Nebraska is at a crossroads with its obligation to Nebraska citizens with developmental disabilities (DD)¹. Several Nebraska Senators have recognized the urgent need to develop a strategic plan to address the current and future needs of citizens with DD and their families. Recent legislation (Legislative Resolution 156) appointed a workgroup to make recommendations for a strategic plan to incrementally reduce the number of persons on the waiting list and to review and make recommendations on the rate methodology established to fund said services. It is intended that this report will serve as a map for future efforts in that regard. The LR 156 Workgroup respectfully submits this report to the Governor, Legislature, and the Medicaid Reform Council.

The group identified challenges in meeting the needs of the eligible Nebraskans with 2,597 requests for services and currently waiting for services, some since 2003. The group used data and facts provided by the Health and Human Services Division of Developmental Disabilities, the expertise of the workgroup members, and input from Nebraska's DD providers to: analyze challenges facing the state in providing adequate services and supports to its citizens with DD; develop position statements and desired outcomes to guide system changes; and recommend specific changes to strengthen the system in meeting its obligation to its citizens with DD and their families. Some of the most pressing challenges facing the state include:

1. Nebraska needs to develop better methods for projecting current and future service demand.
2. Nebraska is challenged to redirect service demand into more economical service delivery alternatives.
3. The Rate Methodology is outdated and needs to be revised. State payments are not based on a realistic appraisal of legitimate provider costs and comparable market wages.
4. The current rate system is not flexible enough to address individuals' changing needs.
5. Quality measurements are not innovative, nor designed to measure outcomes for people.
6. The current billing and reimbursement systems are outdated and do not promote efficient and effective accounting practices for providers.

The LR 156 Workgroup spent considerable time and deliberation in developing desired outcomes and recommendations to address identified challenges. Specifically, position statements and desired outcomes are listed below.

1. Individuals with DD must have access to and receive necessary publicly funded services and supports with reasonable promptness.
 - a. A full range of quality DD services and related supports are available to all eligible people with developmental disabilities in all areas of the state.
 - b. Providers are funded at a rate and in a method that allows them to hire, train, and retain quality staff to serve current and waiting list populations.
2. Individuals with developmental disabilities must have a variety of quality service and support choices and providers must have flexibility in service delivery.
 - a. Services address all needs of the individual and are based on individualized outcomes and choice.
 - b. Flexibility in funding authorization, service delivery, and definitions is allowed.

¹ The term "intellectual and developmental disabilities (I/DD)" is the term preferred by the American Association of Intellectual and Developmental Disabilities. For purposes of this document, in keeping with current terminology in Nebraska State Statutes and regulations, the term "developmental disabilities" is used.

3. The developmental disability and supporting systems must promote effective and efficient delivery of services and supports.
 - a. The service rate methodology is adequate to support the current and future community service system.
 - b. Nebraska will strengthen the DD system infrastructure, at both the provider and state level, to support a growing community service system.
 - c. Capacity is expanded by developing a flexible system that allows for creativity in developing the supports and services for each person.
 - d. Gains made in public schools are maintained by seamless transition to appropriate services in the community.

Specific recommendations to reach the desired outcomes are presented throughout this report and summarized in the chapter entitled *Summary of LR 156 Workgroup Recommendations*. The recommendations are specific to waiting list reduction, rate methodology, and system changes. Of utmost importance are the two options (below) brought forward to reduce the waiting list. It is to be noted that Option #1 is the preferred strategy for reducing the waiting list. It ensures that funding will be available through upcoming years to fully fund the waiting list.

Option # 1: Appropriate funds, in the upcoming fiscal year, necessary to provide services for all eligible individuals with developmental disabilities who are past their need date. Once those individuals have been funded, provide funding for all eligible individuals as they reach their need date.

Option #2: Incrementally provide services to individuals on the waiting list by offering funding for two years of service requests in each year from 2009 until 2014 and, from that point forward, fund all eligible individuals on their need date.

The workgroup is in agreement that the waiting list cannot be eliminated without an infusion of funding to better support Nebraska providers and changes to the rate methodology. The workgroup recommends that the rate methodology be revised and that a 15% increase be immediately allocated to support the development of needed statewide capacity to serve all citizens on the waiting list. Furthermore, the workgroup recommends that a rate methodology study be undertaken to modernize the current formula that was developed in 1992, as it does not reflect the current environment in which the providers must manage their businesses. Finally, the LR 156 Workgroup recommends that a committee or task force be appointed to monitor implementation and results of the waiting list reduction plan and systems recommendations presented in this report.

Funding the waiting list will not only provide improved quality of life for persons with developmental disabilities and their families, it will also provide thousands of jobs for citizens throughout the state of Nebraska. These are jobs that will put money into the pockets of Nebraskans, as well as stimulate communities by the purchase of goods and services needed to sustain individuals in their chosen communities. Providing services and supports for persons with developmental disabilities will allow them to become more independent, productive citizens, and decrease their reliance upon public support. The economic impact for Nebraska of this important initiative cannot be overlooked nor understated.

It is the sincere hope of the workgroup that Nebraska will follow through with its obligation to aid persons with developmental disabilities and their families to receive the assistance they need to live happy, healthy, and productive lives in their chosen Nebraska communities.

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LR 156 WORKGROUP BACKGROUND

STATEMENT OF CHARGE

Subsection (3) of section 83-1216 in Nebraska statute (the Developmental Disabilities Services Act) states that: “It is the intent of the Legislature that by July 1, 2010, all persons determined to be eligible for services shall receive services in accordance with the Developmental Disabilities Services Act.” With a lengthy list of persons waiting to receive services and inadequate funding, Nebraska is clearly not on target to meet this intent.

Legislative Resolution 156 (LR 156) of the first session of the One Hundredth Nebraska Legislature established a workgroup to address two major issues related to the provision of services to persons with developmental disabilities. The charge for the workgroup, as defined in LR 156, is as follows:

- (1) Submit recommendations for a strategic plan to incrementally reduce the number of persons on the waiting list for developmental disabilities to meet the intent of the Legislature;
- (2) Consult with the Department of Health and Human Services to review and make recommendations on any revision to the rate methodology; and
- (3) Submit the workgroup’s recommendations on the strategic plan and revisions to the rate methodology in a report to the Medicaid Reform Council, the Legislature, and the Governor.

PROCESS

Through a series of four facilitated meetings in the fall of 2008, the workgroup met to identify and develop a common understanding of the issues related to the waiting list and funding methodology. Reports and recommendations from previous state initiatives were reviewed and considered, with recognition given that these are not new issues.

A vast amount of data was compiled by the Department of Health and Human Services Division of Developmental Disabilities (DDD) and reviewed by the workgroup throughout the course of this process. This information included: current and future waiting list numbers, historical usage of funding, attrition figures, and projected numbers of students exiting high school. Additionally, information was provided and discussed regarding the current process for being placed on the waiting list, determining priority for receiving services, and other information regarding the waiting list and funding methodology. This data and information is presented throughout the body of this report and the appendices.

RECOMMENDATIONS

As a final and culminating step, a set of recommendations to be used in the development of a strategic plan to address the waiting list and funding methodology was developed by the workgroup. The complete set of recommendations is included in the chapter entitled: *Summary of LR 156 Workgroup Recommendations*. A comprehensive strategic plan for the delivery of DD services will need to take into account the information and recommendations provided by this group, as well as the work of other initiatives related to the service system, e.g., the BSDC Oversight Committee, the Objective Assessment Process Workgroup, etc.

A draft of this report was presented to the Nebraska Planning Council on Developmental Disabilities for their review and finalization, with changes made as per their recommendations. This document is the final report submitted to the parties identified in the Legislative Resolution.

Recommendations are organized in this report as follows:

Waiting List Reduction: Funding options for reduction of the waiting list are provided for consideration, as well as recommendations that may have a direct or indirect impact on the waiting list.

Rate Methodology: Recommendations are made to address the rate methodology changes that the workgroup identified as necessary to support the current and future community service system.

System Recommendations: Recommendations are provided for systemic changes that would positively impact the developmental disability service system.

Oversight Plan: An oversight plan is recommended to monitor implementation and results of the LR 156 recommendations.

Related DD System Issues: As the workgroup conducted their activities, other critical issues related to the developmental disabilities service system were identified. While not directly related to the waiting list or funding methodology, the group felt that it is imperative that these are addressed in order to provide a comprehensive system of services for persons with developmental disabilities.

UNDERSTANDING THE WAITING LIST

The following information is designed to assist in understanding how Nebraska offers developmental disabilities services to eligible individuals. It should be noted that The American Association of Intellectual and Developmental Disabilities (AAIDD) recommends the use of the term “intellectual disabilities” in combination with the term “developmental disabilities”. For purposes of this document, in keeping with current terminology in Nebraska State Statutes and regulations, the term “developmental disabilities” is used. As we move toward the change in terminology, the AAIDD definition of intellectual disability is provided as follows for future reference.

“Intellectual disability is the currently preferred term for the disability historically referred to as mental retardation. Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability and the need of people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.”²

Much of the information presented in this section was adapted from the “Planning Better Futures Report on Nebraska’s Waiting List Initiative”, submitted to the Nebraska Unicameral by the Arc of Nebraska and the Nebraska Planning Council on Developmental Disabilities in 2000.

How does an individual become eligible for DD services?

Any Nebraska resident who has a developmental disability (DD) is potentially eligible for services from Nebraska Health and Human Services. Eligibility for DD services is defined according to the Developmental Disabilities Services Act. The eligibility determination process is completed at the local DD Service Coordination office.

What is the Division of Developmental Disabilities (DDD) Registry?

Once an individual is determined eligible, the individual or family indicates the date that services will be needed. This is commonly termed the individual's “need date”. It could be the same day or a date in the distant future. This information is placed on the DDD tracking system known as the Registry. Individuals and their families are encouraged to get an individual’s name on the DDD Registry as soon as possible, whether the need date is immediate or years away.

What happens when the need date occurs?

The individual is considered to be on the waiting list when the stated need date has been reached or passed. The term “waiting list” is not an official term, but is used to refer to individuals with DD who have requested services, have a need for services, but cannot receive services primarily due to lack of funding.

Historically, as funding has become available for those on the waiting list, the order of selection has been by stated need date. In other words, those who have surpassed their stated need date in the most distant past receive services before those whose stated need date is more

² American Association of Intellectual and Developmental Disabilities: <http://www.aamr.org/>

current. Under special initiatives in the past, there have been instances where other priorities for funding have been established.

Who currently receives DD services?

Individuals who are currently receiving services (either day or residential services), continue to receive services until they no longer need the services, choose to exit services, leave the state, or are deceased. Service Coordination is offered to all individuals deemed eligible. Services are also offered to:

- Nebraska youth who graduate from a Nebraska high school, are age 21, and are on the DDD Registry. These graduates are offered day services and Service Coordination. They typically do not receive residential services, even though they may need and have requested them. This is due to lack of funding. So, if they need services besides day services and have requested such, they remain on the waiting list.
- Eligible individuals demonstrating an emergency need (as defined in state statute).

What if there is an emergency situation?

Based upon statutory language, Nebraska uses a system of authorizing services based upon emergency needs. Individuals in a situation that is deemed threatening to their health or safety, as defined by state statute, are termed as Priority One status. These individuals receive day and/or residential services based upon their assessed need.

What happens if an individual over 21 with DD moves into Nebraska from another state?

Eligibility for services in another state does not mean the individual will be eligible in Nebraska. The individual must be determined eligible by Nebraska's standards and, if eligible, will be placed on the DDD Registry. Unlike individuals exiting a Nebraska high school, they are not entitled to day services, but could receive Service Coordination if requested.

How is the amount of services for each individual determined?

The Objective Assessment Process (OAP) assists in determining the individual's level of need. The assessment is performed by using a standardized assessment tool, the Inventory for Client and Agency Planning (ICAP). Once the OAP is completed, a level of need is calculated and used to determine the amount of funding available for that person. The phased-in implementation of the OAP began in 1998. Individuals new to the system since 1998 receive the amount of funding determined by the OAP. Adjustments based on the OAP have not been made for individuals receiving DD system services prior to 1998.

What are the types of services offered?

Services are considered to be either specialized or non-specialized. Specialized habilitation services are those designed to teach an individual skills as specified in their Individualized Program Plan and delivered by a certified DD provider. Non-specialized services are designed to provide support to the individual and are provided by individuals or agencies independently chosen and hired by the individual and his/her family. Further explanation of these services may be found in Appendix B.

Specialized Services

Service Coordination: working with the individual and their family to develop plans for meeting the individual's needs.

Day/Vocational Services: services designed to assist in becoming employed. Services may range from supporting the person in a job in the community to teaching job skills in a sheltered setting.

Residential Services: services designed to assist the individual in living in the community. Services may be provided in the person's home or in supervised settings in the community.

Respite: service designed to provide occasional relief to the family from the day-to-day care and supervision of the individual.

Non-Specialized Services

The Community Supports Program (CSP) is a system of self-directed services, planned by the individual and their family. CSP services are not based upon the habilitation (training) model, but rather upon a model of flexible services and support.

Services offered under the CSP include:

- Community Living and Day Supports
- Assistive Technology and Supports
- Home Modifications
- Personal Emergency Response
- Vehicle Modifications
- Respite

SERVICE UTILIZATION

Current Service Utilization

Nebraska's 33 public and private community-based providers serve 4,512 individuals in 70 certified programs.

Historical Service Utilization

Figure 1. provides a breakdown of service utilization by service type since 2004. The number of persons utilizing each service type has climbed each year except for residential services, which decreased from year 2006 to 2007. The Community Supports Program currently supports 59 individuals and is not depicted on the graph in Figure 1.

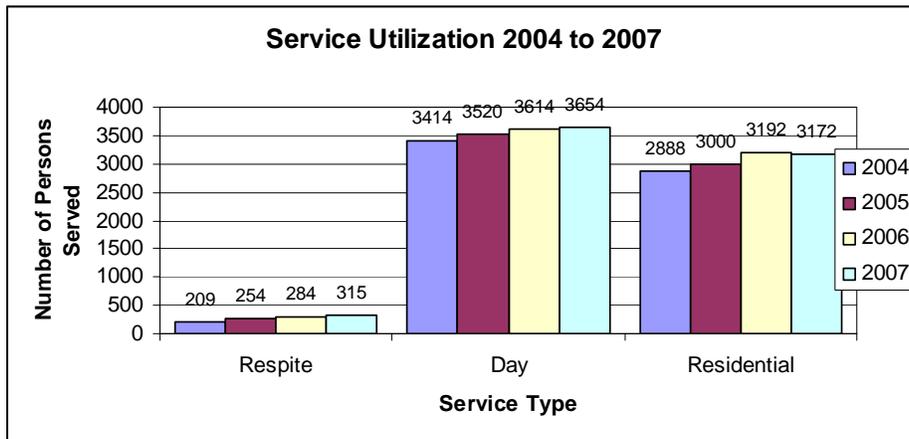


Figure 1. Service Utilization 2004 to 2007

DIVISION OF DEVELOPMENTAL DISABILITY REGISTRY DATA

The Division of Developmental Disability (DDD) Registry Data can be most easily understood by conceptualizing the data into three categories. The data compiled for this report was current as of November 14, 2008. Service requests for 2009 and 2010 are estimates based on average service requests between 2003 and 2008.

The BIG Picture data demonstrates requests by service type through the end of the year 2010.

The CURRENT Picture data demonstrates requests by service type of the individuals currently waiting for services or, in other words, past their need.

The FUTURE Picture data demonstrates requests by service type for the individuals who will reach their need date by the end of the year 2010.

The BIG Picture

Registry data reported on November 14, 2008 indicates a total of 3,465 requests for service by individuals past their need date and reflects estimated requests for services in 2009 and 2010. The data indicates 494 requests for respite services; 630 requests for day services; and 2,341 requests for residential services, for a total of 3,465 requests. (Figure 2.)

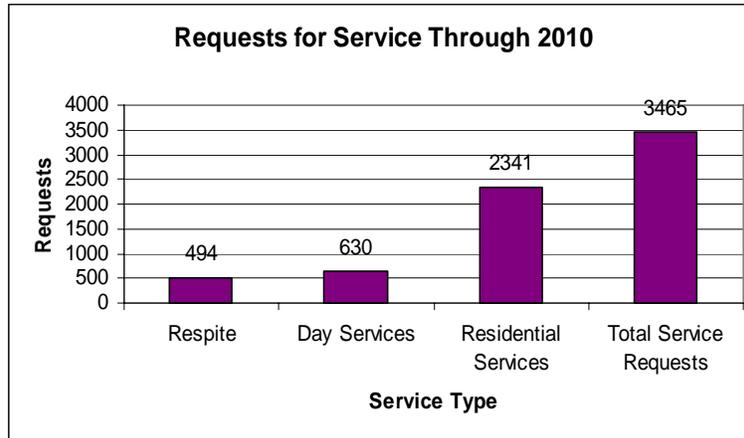


Figure 2. All Service Requests Through 2010

***Service Requests for 2009 & 2010 are Estimated**

The CURRENT Picture

As of November 14, 2008 there are 2,597 requests for service on the DDD Registry from individuals who are past their stated need date and waiting for day, residential, and/or respite services. Some of these individuals have been waiting five years for services. The data indicates 370 requests for respite; 472 requests for day services; and 1,755 requests for residential services for a total of 2,597 requests for service. (Figure 3.)

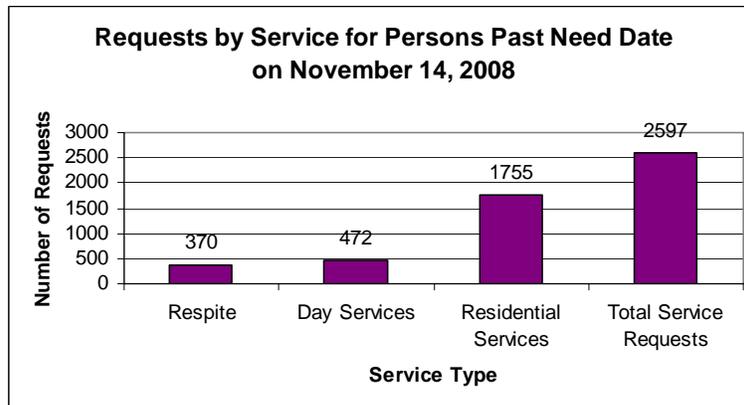


Figure 3. Service Requests for Persons Past Need Date as of November 14, 2008

The FUTURE Picture

Based on average service requests between 2003 and 2008, it is estimated that 868 service requests will be registered in 2009 and 2010. Estimates indicate that 124 individuals will request respite services; 158 individuals will request day services; and 586 individuals will request residential services, for a total of 868 requests for service. (Figure 4.)

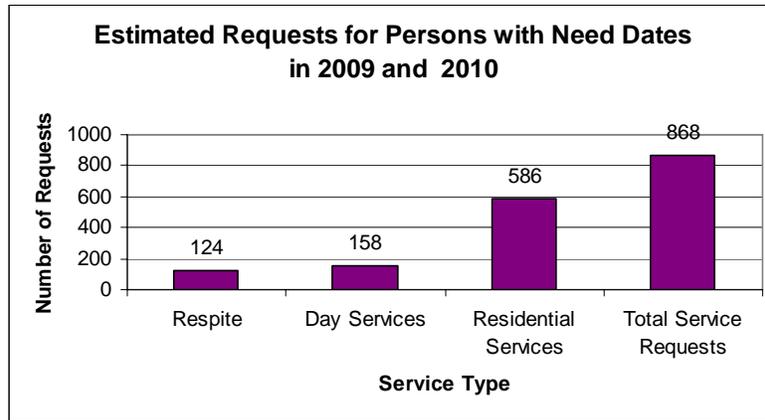
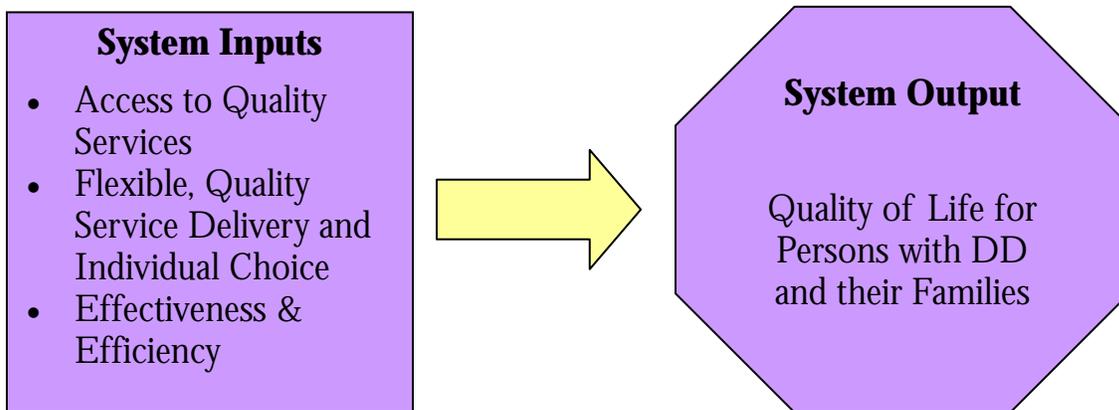


Figure 4. Estimated Service Requests with Need Dates in 2009 and 2010

POSITION STATEMENTS AND DESIRED OUTCOMES

It is clear that Nebraska is underperforming in meeting its obligation to citizens with developmental disabilities. In response, fundamental system changes are necessary to improve Nebraska's performance in supporting this population and in meeting its enormous waiting list obligation. Absent change, system performance will not improve appreciably; the waiting list will continue to grow; individuals and families will not be served or will be underserved; and the entire system will deteriorate over time, resulting in undesirable outcomes for persons with DD and their families.

The LR 156 Workgroup spent considerable time and deliberation in analyzing the system's challenges and developing recommendations to address identified needs. The recommendations are key to fully funding the waiting list and redesigning the system to better meet current and future needs of this population. The recommendations are based on the premise that access to quality services; flexible, quality service delivery and individual choice; and system effectiveness and efficiency will lead to quality of life for persons with developmental disabilities and their families.



To that end, the workgroup developed three position statements and the desired outcomes for achieving the system changes required to meet the needs of individuals with DD in Nebraska.

POSITION STATEMENT #1: ACCESS TO QUALITY SERVICES

Individuals with developmental disabilities must have access to and receive necessary publicly funded services and supports with reasonable promptness.

Currently, Nebraska has fallen significantly short of providing services and supports with reasonable promptness to citizens with DD. Data presented earlier in this report is evidence of the lack of progress in this area. The last year that individuals on the waiting list were offered services was 2006 and, at that time, the list was caught up to serve individuals who had been waiting since 2002.

There are 2,597 requests for services by eligible individuals who are past their need date on the DDD Registry. Some of these individuals have been waiting five years for services. Every year the waiting list continues to grow, so if action is not taken now, the problem will continue to significantly increase in future years. It is estimated that 434 service requests will be added to the DD Registry annually. The list only continues to grow.

Desired Outcomes

The workgroup identified the following as desired outcomes in providing access to quality services for persons with developmental disabilities:

- A full range of quality developmental disabilities services and related supports are available to all eligible people with developmental disabilities in all areas of the state.
- Providers are funded at a rate and in a method that allows them to hire, train, and retain quality staff to serve current and waiting list populations.

POSITION STATEMENT #2: FLEXIBLE, QUALITY SERVICE DELIVERY AND INDIVIDUAL CHOICE

Individuals with developmental disabilities must have a variety of quality service and support choices and providers must have flexibility in service delivery.

The term “flexibility” was a major theme that continued to surface during workgroup discussions. Changes to promote flexibility in regulations, service delivery settings, individual use of funds to purchase supports in addition to habilitation services, and funding methodologies need to be explored, developed, and implemented. Such changes would offer a variety of quality service and support choices for individuals, as well as allow providers flexibility in methods of service delivery.

Individuals with DD often have complex needs that are not adequately addressed, particularly those individuals with behavioral challenges related to mental illness (also known as “dual diagnosis”). DD providers struggle to support individuals with a dual diagnosis and the behavioral health system and community law enforcement agencies are unprepared and, at

times, unresponsive to cries for help from families and providers. Cross-system responses need to be developed to better serve these individuals, as well as resources for persons with traumatic brain injury, medically complex conditions, and autism.

Individuals and their families often choose more expensive, assisted services in which they are assured a staff member is continuously present. Many of those who choose this level of service may be able to have their needs met by supported services in which staff are not continuously present. However, they tend to choose assisted services because “safety net” policies and procedures, which allow them to return to a more intense level of services if less intensive services do not work out, are not in place.

Desired Outcomes

The workgroup offers the following as desired outcomes in order to provide flexible, quality service delivery, and individual choice.

- Services address all needs of the individual and are based on individualized outcomes and choice.
- Flexibility in funding authorization, service delivery, and definitions is allowed.

POSTION STATEMENT #3: EFFECTIVENESS & EFFICIENCY

The developmental disability and supporting systems must promote effective and efficient delivery of services and supports.

An effective and efficient system is critical to the delivery of effective and efficient services and supports. The system is sustainable when it utilizes cost effective services and supports, builds upon the supports of families and communities, and effectively utilizes federal funding.

Capacity of providers to hire and retain a quality workforce to deliver services is an ongoing challenge. In order to serve additional individuals, providers will need a mechanism to access funding for start-up costs as they develop new services and supports for persons entering the system.

Capacity concerns are also an issue for the infrastructure of the entire system. As additional persons leave the waiting list and enter the service system, the demands at the State-agency level will increase. Additional Service Coordinators will be needed; administrative implementation and oversight needs will increase; education and training will need to be provided; and billing and tracking systems will need to be responsive to change.

The LR 156 Workgroup expressed strong support of the concepts of the Community Supports Program (CSP), but recommended changes to the program to allow for increased availability and flexibility for individuals and their families. Nebraska’s experience with this relatively new program has been quite positive and is supported by national trends regarding self-directed service models. Experience in Nebraska and other states show that the cost of CSP supports is significantly less than those in the traditional service models.

The system is sustainable when it utilizes cost effective services and supports, builds upon the supports of families and communities, and effectively utilizes federal funding.

Given the flexibility, affordability, and satisfaction with the CSP, it is strongly recommended that emphasis be placed on expansion and improvement of this service-delivery model.

Recognizing that the system cannot operate in isolation, recommendations are also made to support youth as they transition from school to community supports and services. Effective transition planning and partnerships between systems benefit young adults and their families and has been shown to decrease the individual's long-term reliance upon publicly-funded services, thus decreasing stress upon the system.

Desired Outcomes

The workgroup offers the following as desired outcomes in promoting effectiveness and efficiency.

- The service rate methodology is adequate to support the current and future community service system.
- Nebraska will strengthen the developmental disability system infrastructure, at both the provider and state level, to support a growing community service system.
- Capacity is expanded by developing a flexible system that allows for creativity in developing the supports and services for each person.
- Gains made in public schools will be maintained by seamless transition to appropriate services in the community.

WAITING LIST REDUCTION

“It is the intent of the Legislature that by **July 1, 2010**, all persons determined to be eligible for services shall receive services in accordance with the Developmental Disabilities Services Act.”

WAITING LIST CHALLENGES

Nebraska is seeking to live up to its obligation to persons with DD as stated in the Developmental Disabilities Services Act. This is a commendable goal and one that can be met with careful planning, systemic changes and, of course, political will. It is important to recognize that Nebraska has many challenges ahead that must be studied, understood, and addressed before a sound strategic plan to reduce the waiting list can be developed. These systemic challenges include:

1. Nebraska needs to develop better methods for projecting current and future service demand.
2. Nebraska is challenged to redirect service demand into more economical service delivery alternatives.
3. The Rate Methodology is outdated. State payments are not based on a realistic appraisal of legitimate provider costs and comparable market wages.
4. The current rate system is not flexible enough to address individuals' changing needs.
5. Quality measurements are not innovative nor designed to measure outcomes for people.
6. The current billing and reimbursement systems are outdated and do not promote efficiency and effective accounting practices for providers.

The challenges are discussed in the three sections which follow: Service Demand, Waiting List Projections, and Service Utilization Costs.

Service Demand

“Most of the 5 million people with DD in the United States are supported by their families or live independently without specialized publicly-funded DD services.”³ The majority of families care for their loved ones for as long as they can possibly do so, but publicly funded DD services are usually necessary at some point. On a national average, publicly funded DD service systems provide services and supports to a relatively small number of eligible individuals. It is estimated that approximately 20 to 25 percent of persons with DD actually receive services. Public systems focus primarily on people who have significant functional limitations, complex service needs, lack a support system, or require services over and above the supports that their family is able to provide. In most cases, once individuals access publicly funded services, they will need to do so throughout their lifespan. Therefore, public officials must plan for funding for them from year to year.

Each year the demand for DD services in Nebraska, as in other states, grows. The increased demand for services is generally a product of several factors. People with DD, like the general population, are experiencing increased longevity. As medical technology advances, all people are living longer. Therefore, an individual's need for DD services is extended over more years. Individuals are staying in the system longer. In addition, people with developmental disabilities

³ Human Services Research Institute. (October 2008). *Closing the Gap in Texas: Improving Services for People with Intellectual and Developmental Disabilities*. www.hsri.org

are outliving their parents or primary caregivers. On average, about 25 percent of people with DD currently reside in households in which the primary caregiver is age 60 or older. As caregivers age, their ability to support their loved ones decreases and the demand for publicly funded services grows.

The demand for developmental disability services is dynamic. That is, the demand is not a static one; it grows from year to year. Nebraska's service demand over the past five years is displayed in Figure 5. The average number of requests in any given year for day services is 79. In 2007, the requests for day services exceeded the average with 116 requests. The demand for residential services has increased even more dramatically over the past five years. Residential service requests range from a low of 195 in 2004 to an all time high of 388 in 2007.

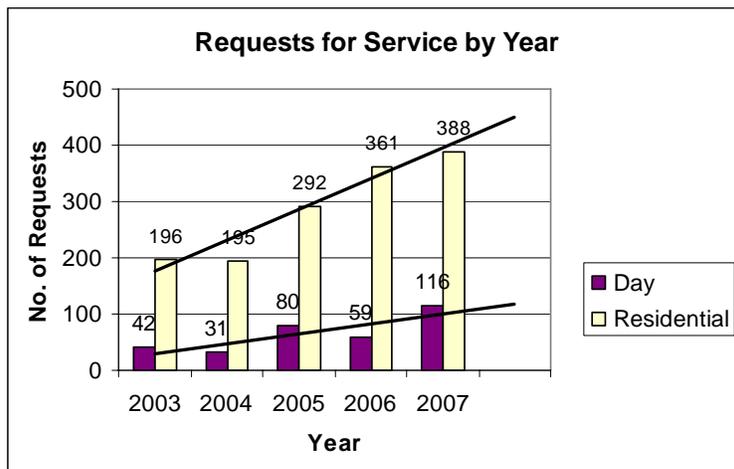


Figure 5. Requests by Service Year

The increase in demand for day services is less dramatic than demand for residential services because DD eligible youth who graduate from a Nebraska high school and are age 21 or over are offered day services and Service Coordination. Separate funding for these services has been included in the annual appropriation for DD services. They typically do not receive residential services, even though they may need and have requested such. So, they are then captured on the waiting list for residential services, but not for day services. On average, 170 high school graduates request and receive day services annually. The average annual funding amount is \$12,000 per year per graduate, for a total of \$2,040,000 per year in state and federal funds.

On average, 170 high school graduates request and receive day services annually. The average annual funding amount is \$12,000 per year per graduate, for a total of \$2,040,000 per year in state and federal funds.

Serving only those with crisis or emergency needs and only funding day services for graduates has resulted in a huge backlog of individuals who need, want, and are eligible for services. Experts note that it is not uncommon to observe a year-over-year increase

in the expressed demand for DD services of four percent or more.⁴ Clearly, Nebraska has not kept up with the demand for services.

“Federal court decisions have clearly indicated that responding to service needs with reasonable promptness means those individuals who have emergency or crisis needs must receive Medicaid-funded services within 90 days.”⁵ Nebraska’s Priority One process is the avenue individuals and families resort to when they find themselves with emergency or crisis needs. Savings from those leaving services (attrition) are utilized to fund Priority One requests. It is questionable if this is the best method to fund the Priority One requests, rather than having a separate funding stream for such emergency situations and utilizing savings from attrition to fund other individuals on the waiting list. On average, 98 people are authorized to receive Priority One funding each year. The average annual cost for those in Priority One status is \$4 million dollars (\$2 million Federal/ \$2 million State).

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Waiting List Projections

Nebraska’s DD service system operates under fixed funding limits. The annual appropriation does not accommodate all eligible Nebraskans requesting services. Therefore, capacity is determined by the annual appropriation and historically, as mentioned earlier, additional system funding only covers day services for graduates. Individuals who want more of a particular service; graduates requesting residential services; eligible individuals who move into the state; or individuals requesting services who have not previously had an immediate need are not served unless Priority One status is determined. These are the individuals who spill over onto Nebraska’s waiting list. Limited funding, coupled with rising demand for services, has resulted in the crisis Nebraska is facing today with a waiting list of 2,597 requests for service by eligible individuals past their need date.

Limited funding, coupled with rising demand for services, has resulted in the crisis Nebraska is facing today with a waiting list of 2,597 requests for service by eligible individuals past their need date.

The process used to formulate the waiting list poses many problems, especially in projecting how many individuals will accept services if offered and determining how much funding will be needed to serve those individuals once services are offered. Eligible individuals are asked to select services (day, residential, respite) they will need and the year they will need it. Based on their individual situation, individuals may request to receive day services in one year and residential services in another year. Individuals are determined eligible before they can be placed on the waiting list, but the level of service (number of units) they are eligible for is not determined at that time. The amount of services the individual needs is not determined until the individual is actually offered the service. This makes it extremely difficult to project how much funding is actually needed for those on the waiting list.

⁴ Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2007). *Residential Services for People with Developmental Disabilities: Status and Trends Through 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

⁵ Human Services Research Institute. (October 2008). *Closing the Gap in Texas: Improving Services for People with Intellectual and Developmental Disabilities*. www.hsri.org

Historically, when offered, 60% of individuals on the waiting list accept day services; 80% of individuals accept residential services; and 70% of individuals accept respite services. The reasons individuals decline services when offered are varied and include: lack of service provider capacity; lack of providers in the home community; available services are not the level or type needed; and/or the individual/family has made other arrangements or adjustments to meet their needs. Of those who decline services, many still need the service but push the need date forward. A very small percentage of individuals turn down services altogether and remove their name from the waiting list. The coupling of the lack of knowledge about the individual's level of need and whether or not individuals will actually take the service once offered makes for a very inexact science when predicting the funding needed to eliminate the waiting list and meet future service requests.

Service Utilization Costs

The most utilized services are assisted services, i.e., those where a staff person is always available. Supported and CSP services are much less expensive and chosen less frequently. Staff are not always available but provide intermittent services and/or support. Data regarding service utilization costs is broken down by residential, day, respite, and CSP in the discussion below.

Residential Services include: Assisted Residential, Extended Family Home, Supported Residential, or In-Home services. The various service definitions can be found in Appendix B.

- Assisted Residential services, primarily provided in a group home setting, are the most costly residential services.
- In the current fiscal year (FY08), 1,770 individuals are receiving Assisted Residential at an average cost of \$45,010.84 per individual per year. (Figure 6. and Figure 7.)
- Fewer individuals choose the less expensive types of residential services, which are Extended Family Home, Supported Residential, and In-Home services.



Figure 6. Mean Cost of Residential Services per Individual (FY08)

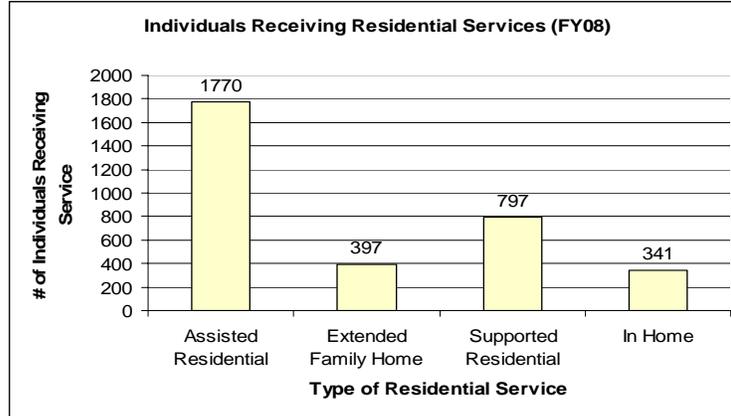


Figure 7. Individuals Receiving Residential Services (FY08)

Day Services include: Assisted Day, Work Station, Supported Day, and Supported Employment.

- The same phenomena holds true in that Assisted Day services, which are primarily provided in workshop settings, are the most expensive.
- The majority of the individuals receiving Day Services have chosen Assisted Day, with 2,802 individuals at an average cost of \$14,118.70 per person per year.
- Fewer individuals are utilizing the less expensive service types of Work Station, Supported Day, and Supported Employment. (Figures 8. and 9.)

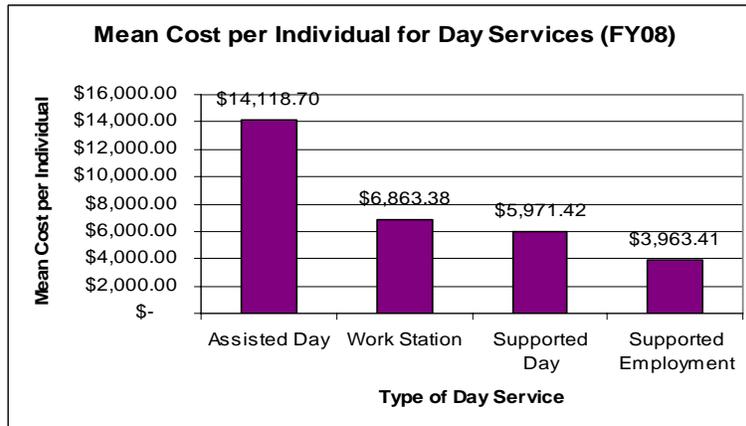


Figure 8. Mean Cost per Individual for Day Services (FY08)

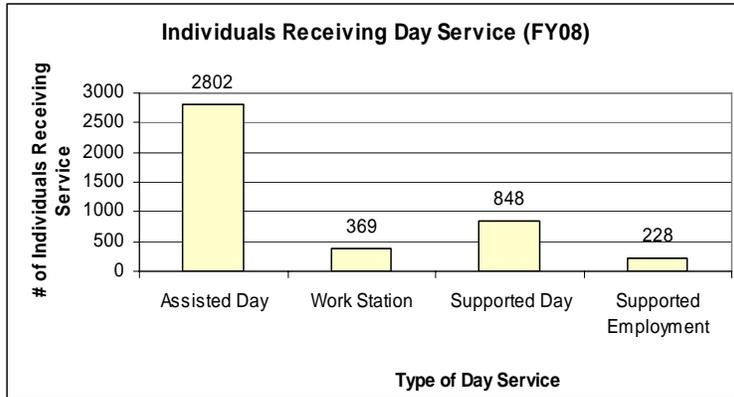


Figure 9. Individuals Receiving Day Services (FY08)

The Community Supports Program (CSP) and Respite services are less expensive and are selected less frequently.

- In the current fiscal year (FY08), 319 individuals are receiving Respite at a mean cost of \$2,501.50 per year per individual.
- The CSP is a relatively new program in Nebraska and offers an array of services, with Community Living and Day Supports and Community Living In-Home Supports being the two most frequently utilized.
- For the current year, 48 individuals receive funding for Community Living and Day Supports at an average cost of \$2,426.03 per individual per year; and 51 individuals are receiving Community Living Supports In-Home at an average cost of \$1,611.77 per individual per year. (Figure 10. and 11)

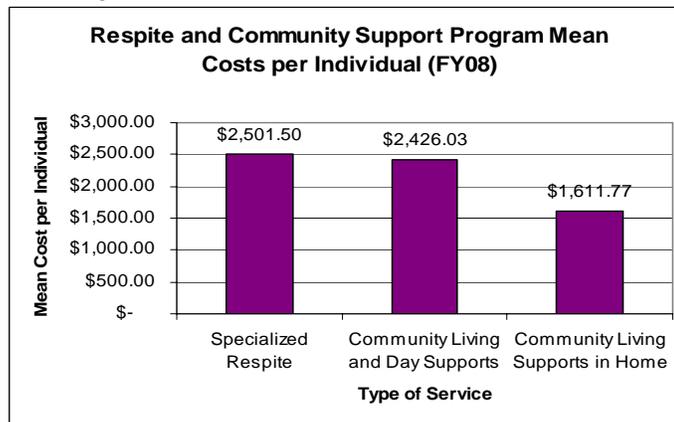


Figure 10. Respite and CSP Mean Costs per Person (FY08)

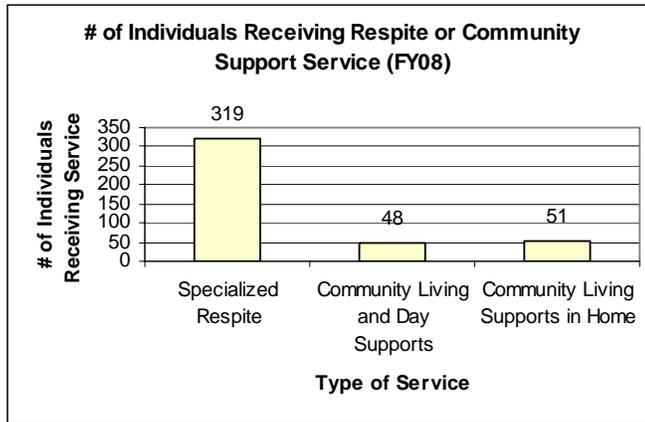


Figure 11. No. of Individuals Receiving Respite or CSP (FY08)

The CSP is an excellent lower cost service choice, and one that provides greater flexibility and control for individuals and their families. There are many reasons why individuals select the service types that they do. Typically, those with needs that are more extensive and who have fewer natural supports request Assisted Day and Assisted Residential services. Individuals with less extensive needs and/or more natural supports can typically be well served in the less expensive service types. Individuals often do not choose the less expensive, less intensive services because of the lack of flexibility and safety net assurances that would allow them to return to a more intense level of service if less intensive services do not work out.

The CSP is an excellent lower cost service choice, and one that provides greater flexibility and control for individuals and their families.

As previously noted, the CSP is a fairly new service option in the state and has yet to realize its full potential. It is anticipated that if more individuals and families, especially youth transitioning out of high school, were well informed about the CSP, they might find that it is a more desirable option than the typical group home and workshop setting.

WAITING LIST FUNDING OPTIONS

As mentioned earlier in this report, some individuals have been waiting for services since 2003. Table 1. represents, by need date (in two-year increments), the number of individuals waiting for each of three service types: day, residential, and respite. Individuals can request one, two, or all three services. This data is based on data obtained from the Division of Developmental Disabilities through November 14, 2008.

Need Date	PROGRAM TYPE			
	Day	Residential	Respite	Total
2003 & 2004	142	698	82	922
2005 & 2006	173	631	110	914
2007 & 2008	157	426	178	761
Total	472	1755	370	2597
Avg. Yearly Growth	79	293	62	434

Table 1. Service Requests by Program Type by Need Date (as of 11-14-08)

The LR 156 Workgroup recommends consideration of the following two options for methods to reduce the waiting list as presented in Table 1. Option #1 is the preferred option.

Option #1: Appropriate funds, in the upcoming fiscal year, necessary to provide services for all eligible individuals with developmental disabilities who are past their need date. Once those individuals have been funded, provide funding for all eligible individuals as they reach their need date.

Option #2: Incrementally provide services to individuals on the waiting list by offering funding for two years of service requests in each year from 2009 until 2014 and, from that point forward, fund all eligible individuals on their need date.

Option #1.

As of November 14, 2008, a projection of \$62,544,700 State and Federal funds is needed to fully fund the waiting list. Taking into account the Medicaid match rate for waiver services and the historical average number of waiver eligible individuals in Nebraska, this results in an approximate 50/50 split for State and Federal funds. **These figures do not take into account any increased rates or changes to the rate methodology, nor do they take into account any additional infrastructure needs, i.e., Service Coordination, additional state level staff, etc. The funds cover only the costs for services calculated on the 2008 rates.** Any unexpended funds during any fiscal year would revert back to the general fund and be set aside for future use in reducing the waiting list. Continued appropriations for subsequent years are necessary to address ongoing need.

Option #2.

Option #2 is presented in Table 2. below. The proposed option is based upon the premise of providing needed funding for two years of service requests in each year from 2009 until 2014. **These figures do not take into account any increased rates or changes to the rate methodology, nor do they take into account any additional infrastructure needs, i.e., Service Coordination, additional state level staff, etc. The funds cover only the costs for services calculated on the 2008 rates.** This will need to be re-calculated each biennium to reflect current actual requests, as well as to reflect those who have changed their need date. The column titled 'New State and Federal Funding + Funding from Previous Year(s)' in the table reflects the funding appropriated in the previous year to fund those on the waiting list *plus* new funding for the year to fund additional people on the waiting list. Funding must be carried forward each year to continue services for those who were newly funded in the previous year.

The service requests are reduced by the percentage of individuals who typically accept services for the year requested, i.e., 60% of day services; 80% of residential services; and 70% of respite services. By the year 2015, the backlog of the waiting list will be eliminated and, from that year forward, individuals must be funded on their need date so that it does not build up to what it is today. The state funding total is calculated at 50% instead of the customary 40% because some individuals do not qualify for Medicaid funding and rely totally on state funding.

Fiscal Year	Years of Date of Need	Day: 60% of Requests	Residential: 80% of Requests	Respite: 70% of Requests	Total Requests Funded	New State and Federal Funding per Year	New State and Federal Funding + Funding from Previous Year(s)	State Funding Portion (50% of Total)
2009-10	2003-2004	85	558	57	700	\$22,995,784	\$22,995,784	\$11,497,892
2010-11	2005-2006	104	505	77	686	\$22,399,790	\$45,395,574	\$22,697,787
2011-12	2007-2008	94	341	125	560	\$17,159,125	\$62,554,699	\$31,277,349.
2012-13	2009-2010*	95	469	87	650	\$22,538,408	\$85,093,107	\$42,546,553
2013-14	2011-2012*	95	469	87	650	\$22,538,408	\$107,631,515	\$53,815,757
2014-15	2013-2014*	95	469	87	650	\$22,538,408	\$130,169,923	\$65,084,961
2015-16	2015*	48	234	43	325	\$11,269,204	\$141,439,127	\$70,719,563

Table 2. Waiting List Reduction in 2 Year Increments

*Based on anticipated growth of the waiting list, not actual requests. Anticipated growth was calculated by averaging requests from 2003 until 2008.

WAITING LIST REDUCTION RECOMMENDATIONS

1. **Funding:** Option #1 to appropriate, in the upcoming fiscal year, the funds necessary to provide services for all eligible individuals with DD is the ideal recommendation to fund the waiting list. Once all individuals on the waiting list are provided services, individuals will be funded as they reach their need date. Option #2 to incrementally provide services to individuals on the waiting list by offering funding for two years of service requests in each year from 2009 until 2014 and, from that point forward, fund all eligible individuals on an annual basis is an acceptable option, but not the preferred option.
2. **Priority One Funding and Savings:** The workgroup recommends the appropriation of a separate fund to serve individuals determined to be Priority One status each year instead of savings from attrition being utilized for Priority One funding. The average annual cost for those in Priority One status is \$4 million (\$2 million Federal/\$2 million State funds). Savings from attrition or efficiencies in the system can then be used to fund individuals on the waiting list.
3. **Community Supports Program (CSP):** Revisions to the CSP to improve its usability and attraction to individuals and families include the following recommendations:
 - The current CSP caps funds available to individuals at \$20,000 or their OAP, whichever is less. Many individuals and family members report that this is too low to meet their needs. The workgroup recommends raising the individual cap.
 - Currently, the rates at which providers can be paid are capped at levels that are reported to be too low to attract and retain quality providers. These caps also limit the ability of individuals to hire specialized DD providers to provide services. The workgroup recommends raising or eliminating these caps.
 - The CSP has not been widely marketed. The workgroup recommends that extensive marketing and promotion of the program be provided to all interested stakeholders.
 - The workgroup recommends increased training and/or assistance to individuals, families, Service Coordinators, providers, and educators to increase the ability of individuals and families to identify and seek individualized services, self-direct services, and make informed decisions.
 - Currently, individuals in the CSP are not allowed to pay a non-legally responsible relative residing with them to provide their services. The workgroup recommends that CSP funds are allowed to purchase support from a non-legally responsible relative residing with the individual. It is also recommended that consideration be given to further changes to this requirement (in line with Federal Medicaid requirements) that might allow legally responsible relatives to be paid for the provision of services. Impact on other state programs would need to be considered. These changes may allow for a more cost-effective method of providing services.

4. **Incentives:** If Option #2 is chosen: provide an incentive for lower cost services by developing a phase-in process to allow individuals on the waiting list and past their need date by one year to choose either supported services or the CSP and receive services immediately. This process would continue until the slots on the associated waivers are filled. (Example: In the first year, all persons with a need date of 2003-2004 would be offered services. In addition, those with a need date of 2005-2006 would be offered the option of receiving CSP services or supported services). It is important that the changes to the CSP, as identified in point #3, be implemented in order to make this a more viable service option.
5. **Infrastructure:** The infusion of more than 2,000 individuals into the DD system over the next five years will result in a need for increased State agency administrative infrastructure to support increased capacity, e.g., Service Coordination, implementation and oversight needs, education, training, etc.
6. **Reporting:** The LR 156 Workgroup and other stakeholders have expressed confusion regarding waiting list numbers and processes. The workgroup recommends that the State develop a system for regularly reporting the status of the waiting list to interested parties, e.g., legislators, those on the waiting list, and other stakeholders.
7. **Safety Net:** Many individuals and their families do not choose the less expensive supported services (staff are *not* always present) over the more expensive assisted services (staff are always available) because they are fearful that if an emergency arises, they will not be able to access the assisted services needed to weather the emergency. The workgroup recommends that safety net policies and procedures be developed that allow individuals to choose CSP or supported services or even exit from those services *without* losing the option to access assisted services.

RATE METHODOLOGY

An obvious concern is the need for revision of the rate methodology by which Nebraska pays DD service providers. Legislators recognized this need in the creation of LR 156, asking for recommendations for revisions to the rate methodology. This is critical, in that the methodology has not had significant review or change since its development in 1992.

DD PROVIDER INPUT

The LR 156 Workgroup asked Nebraska DD providers to weigh in on the current rate methodology. The methodology has been a major source of tension within the service delivery system for many years. The following points serve as a basis for understanding the history of the rate methodology. Documents supplied to the workgroup by the DD providers can be found in Appendix C.

1. The basic premise of the funding methodology and intervention unit system was to provide "portability" so people could choose any provider and have the money follow the person.
2. People with higher need levels receive greater support than those with lesser need levels; the hope was to provide "no more, no less" than what a person needs.
3. Consistency is achieved by an Objective Assessment Process (OAP) using the Inventory for Client and Agency Planning (ICAP) to determine the number of intervention units. All providers are reimbursed at the same rates for the same services. How well this works in terms of individual equitability can be questioned, but it is a consistent process. It should also be noted that the OAP has not been implemented for hundreds of people who were "grandfathered" into the system when it was implemented for new people entering the system several years ago; therefore, consistency on how the amount of service each individual is receiving does not currently exist.
4. The Medicaid Waiver provides 59.54% federal funds and the state provides 40.46% of the funds when a person is served under a Waiver. Since not everyone is eligible for a Waiver, it averages to be a 50/50 split in costs. It is important to ensure that, when people are authorized for services, Waiver eligibility is immediately sought in order to maximize federal funding.
5. The direct personnel category of the funding methodology is based on 90% of the entry-level salary of a part-time temporary Developmental Technician I (DT I) at the Beatrice State Developmental Center (BSDC) instead of the average salary of a full-time Developmental Technician II (DT II) position. Current rates under the methodology are much lower than the 90% due to recent salary increases at BSDC. The major increased costs in human services have been in the area of benefits, due to increased cost of health insurance, worker's compensation insurance, and other benefits. Benefits originally computed at 20% of salary in the model are closer to 40% today.
6. The funding methodology has not been adapted for higher transportation costs, medical services support, issues around "sleep time" and increased regulation. In addition, there are issues regarding reimbursement for staff time in group homes for overnight

coverage. There are also higher costs for certifying medication aides and licensing of residential settings that impact the cost of doing business which are not reflected in past rate increases.

While there are many issues concerning the funding methodology and practices that affect the waiting list, the primary factors can be categorized as *funding adequacy*, *funding flexibility*, and *accountability*.

Funding Adequacy

While it is clear that money is not the only barrier to staff recruitment and retention, it is perhaps the most critical factor. The current funding methodology includes reimbursement amounts for six different cost categories for each service: direct personnel, direct management, indirect management, non-personnel operating, transportation, and facility costs. When the rate methodology was developed, the Direct Personnel cost category was based on 90% of an entry-level salary position at BSDC. That entry position is now rarely used because of an inability to recruit for that position.

DHHS previously billed the Federal government at 100% of the methodology, but paid providers at 90% of the methodology. DHHS stated that providers came up with the other 10% through county funds and other sources. Recognizing that providers were not receiving 10% from the county or other funds, the State began billing the Feds at the 90% rate they were paying providers, effectively lowering the methodology by 10%.

There are two references to 90% in these discussions that may be confusing. The rate was built on 90% of the salary of BSDC's DTI position, with the idea that providers would be paid less than the State pays staff who deliver similar services at BSDC. Then, as noted above, DHHS said that 10% of the methodology amount was being provided by county funds and other sources so the State would only fund 90% of the methodology rate, further reducing the ability for providers to adequately fund their direct service positions.

In addition, recent salary increases at BSDC have caused providers to fall even farther below the 90% level. Funding should be based on the average BSDC's DTII salary, not entry level of DTI. Providers need to be able to recruit and retain quality staff for a quality service to be delivered. The methodology was developed to support people with DD through habilitation, i.e., training. The people supported today have broader needs than the funding for habilitation envisioned.

Funding Flexibility

The current system of intervention units does not have the flexibility to respond to changes in individuals' lives due to health issues, behavioral issues, seasonal changes, and family situations. Because the State of Nebraska cannot afford to provide one-to-one supports for everyone who needs staff available at all times, some support is provided in groups. This demands flexibility of funding.

The current system offers a method, while less than ideal, to develop a more flexible method to address individual needs. It is proposed to multiply the rates by the approved units to develop a monthly rate for the supports provided to an individual. A monthly unit reimbursement system would assist providers to ebb and flow with individuals' lives. The idea of this is that providers would furnish

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supports that are more intensive during times when an individual has higher needs and back off when those needs lessen.

Accountability

It is important to the Nebraska taxpayer and providers, as stewards, to provide accountability for the use of public funds. It is an equally important facet of stewardship to develop processes that are efficient and effective in delivering outcomes that are desired by the people who receive support and their families. While the State reimburses for each individual, they recognize the need for using staff effectively and the number of units are based on a number of individuals receiving support at the same time.

Accountability should focus on the person receiving supports rather than staff and the billing system. Innovative, efficient, and effective methods of delivering the outcomes that people want and need must be developed. Monitoring processes should focus on the use of mechanisms such as Service Coordination monitoring reports, Quality Review Teams, certification processes, critical incident reporting, family involvement, etc. to determine whether the supports have been provided in accordance with the Individual Program Plan.

Service Delivery System Capacity

Service providers struggle to survive in the face of low payment rates that, in turn, result in major problems in meeting basic quality standards and maintaining workforce stability. There is broad agreement among Nebraska DD service providers that the rates that are paid for DD services are insufficient to ensure the delivery of high quality, effective support for individuals. These enduring low rates in Nebraska are a major source of discussion within the service delivery system.

The LR 156 Workgroup again turned to providers to address the issue of their capacity to serve individuals on the waiting list. Providers reached consensus that, if the following criteria are met, they could develop capacity to respond to an incremental plan to serve all of the individuals on the waiting list.

1. There is a 15% increase in rates to build capacity to serve additional individuals, as well as to attract and retain quality staff.
2. Authorizations for individuals are enough to meet their actual needs.
3. Behavioral health supports are available for dually diagnosed and/or behaviorally challenged individuals.

RATE METHODOLOGY RECOMMENDATIONS

1. **Rate Methodology Study:** The current rate methodology was developed in 1992. It is way past time to develop a rate structure to meet the demands of today's economic environment. In addition, providers have increased demands which did not exist in 1992, including the provision of medical support services; issues around "sleep time"; and increased regulations. The workgroup recommends that the State pursue an independent contract to develop a more appropriate funding methodology and to develop funding alternatives. Among the changes to be considered are:
 - Development of a monthly rate for assisted services.
 - Development of a separate and distinct funding process that includes provider start-up costs to build capacity to serve people from the waiting list.
2. **Provider Rate Increase:** Whether or not a rate methodology study is conducted, providers will require extra funding if the more than 2,000 individuals on the waiting list through 2010 are to be served. The providers are strapped to pay direct service personnel a decent wage and cover the costs of employee benefits and transportation, which have increased tremendously over the past sixteen years since the rate methodology was developed. An increase of 15% in provider rates to build capacity and meet on-going costs of doing business is needed so providers can hire and retain employees and cover actual costs.
3. **Unexpended Funds:** There is a general belief that any DD funds not utilized during a fiscal year are returned to the General Fund. If this is the case, it is recommended that any unused funding allocated to the DD system should be applied to serving persons on the waiting list.
4. **Electronic Billing:** The current billing and reimbursement system needs revision and, if updated, could be a cost saver for the State and providers. An electronic billing and reimbursement system should be developed to reduce errors and provide effective tracking and reporting systems.

SYSTEM RECOMMENDATIONS

This report has outlined specific recommendations to be used in the development of a strategic plan for addressing the waiting list and rate methodology. Through the workgroup process, other system recommendations were developed that are critical to achieving the ultimate goal of providing quality of life for Nebraskans with developmental disabilities. Those recommendations follow.

- 1. Service Models:** The current service models do not address the complex needs presented by some individuals. The workgroup recommends the development of service models to concentrate on the needs of all eligible people within the definition of DD, including those with traumatic brain injury, autism, dual diagnosis, and medically complex conditions. This should include utilizing resources such as Telehealth technology to promote access to specialized professionals, e.g., mental health services.
- 2. Assistive Technology:** Assistive technology is tremendously underutilized in our state. The workgroup recommends increasing access and use of assistive technology for all ages.
- 3. Transition Practices:** Transition planning for high school students is not always done in coordination with adult agency providers, resulting in missed opportunities for youth. The workgroup recommends increased partnerships between the education system, DD system, and Vocational Rehabilitation to provide seamless transition for students as they move from school to adult life. Schools, DDD, and Voc Rehab need to collaborate in the pursuit of real jobs for students during the last two years of school. It is also recommended that increased efforts are made to promote postsecondary education as an option for transition students.
- 4. Provider Employee Development:** Quality direct service workers are worth their weight in gold. The workgroup recommends the funding of a comprehensive system of provider personnel development to assist in direct service worker retention. This may include the development and funding of initiatives such as career ladders, employee incentives, and educational benefits.
- 5. Certification Procedures:** Certification processes are cumbersome for new, small providers to navigate. The workgroup recommends the revision of certification procedures to encourage the development of small and possibly single service providers.
- 6. Individual Use of Funds:** Individual use of allotted funding is tightly controlled. The workgroup recommends greater flexibility in the individual's use of their allotted funds to purchase supports to meet their needs and to receive services in settings that make sense for the individual, e.g., providing day services in the home.
- 7. Regulations:** It is a general perception that state regulations are often more restrictive than necessary, reducing flexibility in providing services. The workgroup recommends that state and federal laws and regulations be interpreted in a manner which allows flexibility (which in some cases promotes the use of less expensive services) whenever possible.

- 8. Pilot Projects to Promote Recruitment/Development of Services:** The workgroup recommends that requests for pilot projects that promote recruitment and/or development of services be sought. Innovative practices in service design and delivery to create a broader range of options to people with DD, especially those who are without services or have fewer options and resources, should be promoted.
- 9. Waiver Expansion:** Nebraska's Medicaid waivers favor services designed to promote habilitation. The workgroup recommends the current waivers expand to include services other than habilitation.
- 10. Objective Assessment Process:** The Objective Assessment Process (OAP) workgroup should be convened to address identified issues related to this process (see "Related DD Systems Issues" section of this report for further discussion).
- 11. Quality Monitoring:** Provider audits currently measure whether staff was present or not during a shift. The workgroup recommends that quality monitoring be measured by outcomes for people rather than whether staff was present. Monitoring should rely upon the use of Service Coordination monitoring reports, Quality Review Teams, certification processes, critical incident reporting, family involvement, etc. to determine whether the supports have been provided in accordance with the Individual Program Plan.

OVERSIGHT PLAN

It is the consensus of the LR 156 Workgroup that an oversight plan is necessary to ensure that:

1. Decision-makers give proper consideration to the recommendations for addressing the waiting list and funding methodology;
2. A strategic plan for implementation of the recommendations is developed;
3. Rationale is provided for any recommendations that are not implemented; and
4. Ongoing monitoring of implementation of the strategic plan occurs.

WAITING LIST OVERSIGHT RECOMMENDATIONS

- 1. Oversight Group:** It is the recommendation of this workgroup that the Nebraska Legislature appoint a committee or task force to monitor implementation and results of the LR 156 recommendations. Funding for the activities of this oversight group will need to be included, as it should not be the responsibility of these agencies to absorb the associated costs. Further, the workgroup recommends representation from the following groups as appropriate members of the oversight committee:

- Nebraska Planning Council on Developmental Disabilities
- Nebraska Advocacy Services
- Munroe-Meyer Institute

These three agencies, funded by the federal administration on Developmental Disabilities (ADD), are part of a national network to build capacity of states and communities to respond to the needs of individuals with disabilities and their families. The role of these three agencies to provide advocacy leadership at a state and federal level to interested persons in Nebraska is a natural fit for this work.

- 2. Technical Advisors:** Appointment of technical advisors representing the following entities is critical to the work of the oversight committee:

- Nebraska Developmental Disabilities Provider Network
- The Arc of Nebraska
- Nebraska Department of Health and Human Services Division of Developmental Disabilities (NDHHS)

- 3. Implementation:** Recommendations of the workgroup related to oversight of implementation include:
 - a. The LR 156 Workgroup report shall be posted on the NDHHS website.
 - b. Periodic status reports shall be provided to stakeholders to reflect:
 - i. decisions regarding implementation of recommendations;
 - ii. updates on waiting list numbers and costs; and
 - iii. steps taken to address the funding methodology.

SUMMARY OF LR 156 WORKGROUP RECOMMENDATIONS

WAITING LIST REDUCTION RECOMMENDATIONS

1. **Funding:** Option #1, which proposes to appropriate funds, in the upcoming fiscal year, necessary to provide services for all eligible individuals with DD who are past their need date is the ideal recommendation to fund the waiting list. Once all individuals on the waiting list are provided services, individuals will be funded as they reach their need date. Option #2 to incrementally provide services to individuals on the waiting list by offering funding for two years of service requests in each year from 2009 until 2014 and, from that point forward, fund all eligible individuals on an annual basis is an acceptable option, but not the preferred option.
2. **Priority One Funding and Savings:** The workgroup recommends the appropriation of a separate fund to serve individuals determined to be Priority One status each year instead of savings from attrition being utilized for Priority One funding. Savings from attrition or efficiencies in the system can then be used to fund individuals on the waiting list.
3. **Community Supports Program (CSP):** Revisions to the CSP to improve its usability and attraction to individuals and families include the following recommendations:
 - The current CSP caps funds available to individuals at \$20,000 or their OAP, whichever is less. Many individuals and family members report that this is too low to meet their needs. The workgroup recommends raising the individual cap.
 - Currently, the rates at which providers can be paid are capped at levels that are reported to be too low to attract and retain quality providers. These caps also limit the ability of individuals to hire specialized DD providers to provide services. The workgroup recommends raising or eliminating these caps.
 - The CSP has not been widely marketed. The workgroup recommends that extensive marketing and promotion of the program be provided to all interested stakeholders.
 - The workgroup recommends increased training and/or assistance to individuals, families, Service Coordinators, providers, and educators to increase the ability of individuals and families to identify and seek individualized services, self-direct services, and make informed decisions.
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These three agencies, funded by the federal administration on Developmental Disabilities (ADD), are part of a national network to build capacity of states and communities to respond to the needs of individuals with disabilities and their families. The role of these three agencies to provide advocacy leadership at a state and federal level to interested persons in Nebraska is a natural fit for this work.
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RELATED DD SYSTEMS ISSUES

As the LR 156 Workgroup conducted activities related to developing recommendations for a strategic plan to reduce the number of persons on the waiting list for DD services and to make revisions to the rate methodology, they recognized that there were other critical issues that need to be addressed by Nebraskans. Although these may not have a direct impact on the waiting list, they cannot be ignored. These issues are so connected that, without making needed changes to all, there is a risk of just transferring a problem from one area to another.

The following issues need to be resolved:

- Changes to the Objective Assessment Process (OAP) need to be considered. The current instrument used is the Inventory for Client and Agency Planning (ICAP). Although individuals are assessed using the ICAP, only individuals new to the system are given the units identified in that formula. Other individuals are authorized at their historical level of service, which may be higher or lower than the ICAP amount. Attempts to make the changes based on the ICAP were stopped, in part, due to concerns about the ability of the ICAP to predict costs of individuals with medical and behavioral health needs. The original plan did not allow for incremental changes, so there were concerns about people being placed at risk if their services were cut dramatically after years of receiving supports. A comparison pilot was done measuring the Supports Intensity Scale (SIS) against the ICAP and policies were put into place to insure safeguards for people losing services. However, the plan was never implemented. Currently, the DD Division has agreed, as part of a lawsuit settlement, to bring a workgroup together to look at this issue again and make recommendations. There are currently individuals in the system receiving fewer services than needed based on their assessments because there is not sufficient funding available to them. It is unclear whether moving people closer to their ICAP amount either up or down would result in additional costs, less costs or balance each other out. It is the recommendation of the LR 156 Workgroup that the OAP Workgroup be convened immediately to address these issues.
- The waiting list does not reflect everyone who is underserved. The waiting list only includes people who are not getting any service in that particular area (residential, day, and/or respite) for which they are on the registry. If an individual accepts any service in an area, they are no longer on the registry for that category of service. This is especially confusing for families who may think they are on the waiting list for a group home when they are getting some in-home supports. The services they are receiving are considered residential supports, so they no longer are on the waiting list in this category. They may be considered underserved and if circumstances change, they may become a Priority One and get the additional units needed to support a group home placement but they are no longer counted in the waiting list. The OAP issue discussed earlier also results in individuals being underserved but not on any waiting list as it is considered a separate issue. At this time there is no record kept at the state level of these “underserved” individuals.
- There are individuals who have a sufficient number of units authorized but because of the geography of where they live, their medical or behavioral health condition, or other factors are unable to find a provider for the needed services. Since the LR 156 Workgroup looked at service capacity issues, it is possible that some of their recommendations in this area will help solve this problem when implemented.

- There are two concerns about youth transitioning from school to the adult service system. First of all, individuals and families continue to lack the accurate information they need to plan for the services and supports that will be needed when they leave school. Although day services are an entitlement to students exiting special education at age 21, residential services are not. Individuals and their families must make appropriate plans for supports the persons needs beyond day services.

The second issue in this area is services for youth who are 18 to 21 years old. Health and Human Services has determined that DD day services are not available until a student reaches 21, regardless of when they graduate. Although this is not an issue for many students who stay in school until they are 21, there are some students who have completed their schooling and would like to graduate and begin paid employment. However, if they opt to do this prior to age 21, they are not eligible for job coaching or assistance in finding and keeping a job. This also limits services that may be provided by Vocational Rehabilitation prior to age 21. Proponents of serving this population maintain that by serving these youth at an earlier age, it is possible to divert them from long term service needs in the DD service system.

- The lack of appropriate and accessible behavioral health services for individuals with DD and mental health concerns is a growing problem in the DD system. Several factors make this a very difficult problem. There is a lack of mental health practitioners that are trained to diagnose and treat persons with DD. The regulations governing DD settings are focused on maximizing independence and so make it difficult to restrict individuals for their safety or that of the community in which they live. Some individuals with severe behavioral health problems function intellectually at the higher end of the scale for DD. The current assessment process measures their functional level and authorizes units accordingly, while it may not take into account the supervision and supports they need because of their mental health problems. As a result, it may be difficult to find qualified providers willing to serve them for the amounts offered. Finally, there is reluctance on the part of the Behavioral Health System and the Division of Developmental Disabilities to assume responsibility for these individuals. Both systems engage in conversations about identifying the “primary diagnosis” in order to say the person belongs in that system rather than trying to figure out how to blend funding and services from both systems to best serve that individual. If services to this population are not provided, it stresses the entire DD system and results in costly institutional placements and Priority One situations.
- Quality assurance must be an essential component of any changes to the community based DD system. The focus must be on insuring that individuals are reaching their identified outcomes. Individuals and families must be confident that the system is assuring basic safety, while being flexible enough to give people choices on how they want to live their lives. Quality assurance and monitoring by the state must allow for flexibility and not be concentrated on paper reviews, but rather observing to determine the quality of life and outcomes that people are achieving.
- Home and Community Based Waivers in Nebraska should be looked at to make sure that they reflect the best practices in the state and nation. They need to maximize federal funds by insuring that all needed services are included. Waivers should allow for self-direction whenever possible. In order to allow people to use the waiver best suited to their needs, eligibility should be based on meeting certain criteria and no waiver should exclude populations if they meet this criteria

APPENDIX

APPENDIX A. LR 156

LR 156 ONE HUNDREDTH LEGISLATURE
FIRST SESSION
LEGISLATIVE RESOLUTION 156
Introduced by Johnson, 37;

PURPOSE:

(1) To examine and provide recommendations relating to the waiting list for people with developmental disabilities and to provide recommendations on any proposed changes to the methodology used for the payment of service providers. The waiting list refers to people who have been determined to be eligible for services, have set a date of need, but have not received services because of a lack of funding available. The waiting list has continued to be only partially addressed and communication, coordination, and collaboration are needed to develop an updated strategic plan based on incremental implementation if the intent of Nebraska law is to be met.

(2) Subsection (3) of section 83-1216 provides: "It is the intent of the Legislature that by July 1, 2010, all persons determined to be eligible for services shall receive services in accordance with the Developmental Disabilities Services Act."

In 2004, LB 297 amended section 83-1216 to include the establishment of a workgroup to provide a report to the Legislature and the Governor for the development of an objective assessment process to determine the amount of funding for the provision of services. The report generated by this workgroup was supported by unanimous consent of the workgroup. Further work is needed to develop a plan and additional study is necessary. Such study and recommendations for a plan shall include, but not be limited to, consideration of the following:

(a) A plan for the provision of services to all persons determined to be eligible for services in accordance with the Developmental Disabilities Services Act by 2010; and

(b) The incremental statewide implementation process for the provision of specialized services based upon:

(i) The number of persons who are waiting for services; and

(ii) The need to prevent any future development of lengthy waiting lists for services.

(3) The plan shall be based upon data provided by the Department of Health and Human Services and the State Department of Education to include, but not be limited to, the following:

(a) The historical usage of priority one funding for people with developmental disabilities;

(b) Attrition in specialized services;

(c) The projected and actuarial budgeted funding for students who are exiting high school; and

(d) Other information as needed.

(4) In addition, the Medicaid Reform Council has identified the need to review and revise the methodology used for determining the rates paid to intellectual and developmental disability providers.

NOW, THEREFORE, BE IT RESOLVED BY THE MEMBERS OF THE ONE HUNDREDTH LEGISLATURE OF NEBRASKA, FIRST SESSION:

To implement the purpose of this resolution, the Department of Health and Human Services shall establish a working group including representatives from the State Department of Education, the Advisory Committee on Developmental Disabilities,

the Developmental Disabilities Planning Council, people with developmental disabilities and their families, a statewide intellectual and developmental disability advocacy organization, developmental disabilities service providers, and other interested parties. The working group shall:

(1) Submit recommendations for a strategic plan to incrementally reduce the number of persons on the waiting list for developmental disabilities to meet the intent of the Legislature;

(2) Consult with the Department of Health and Human Services to review and make recommendations on any revision to the rate methodology; and

(3) Submit the workgroup's recommendations on the strategic plan and revisions to the rate methodology in a report to the Medicaid Reform Council, the Legislature, and the Governor.

APPENDIX B. SERVICE DEFINITIONS

Vocational

Assisted Day/Vocational: staff is on site and immediately available at all times.

Supported Day/Vocational: staff is periodically available and is not constantly on site/available. Services may be provided at work sites where persons without disabilities are employed or volunteer.

Work Station in Industry: workstations are located in a community business or industry where persons without disabilities are employed and where there may be several persons working on different job duties or contracts. Staff is available to people receiving these services at all times. The provider may contract with business or industry. Examples may include enclaves, workstations, or mobile work crews. Workstations do not include provider workshops.

Residential

Assisted Residential: staff is available at all times-including sleep time. Services may be provided in group homes, apartments, or other living environments.

Supported Residential: Services are provided in a residential setting where the person is responsible for maintaining their own home, both financially and domestically, with periodic supervision/support from staff.

In-Home Habilitation: this service is provided to people living with their family to support the individual and family and to prevent out-of-home placements.

Extended Family Home: people receiving these services do not live with their natural families or in settings operated by a DHHS certified provider. Extended families provide service in their own homes and must be available to provide habilitation when the person is home (day and/or evening). Room and board is paid by the person with the disability and the board should include three meals each day.

Home Teacher: home teachers are employees of a certified provider agency. Individuals do not live in their natural family homes. Services are provided in a home teacher's home where a home teacher must be available during the day and/or evening, including sleep time. Room and board (three meals daily) are provided at the expense of the person with the disability.

Respite

Respite services are available for persons living at home with their non-paid family or caregiver. Respite may be provided in the person's home or in a setting operated by a DHHS certified provider.

Source: 2008 DDD Provider Profile

COMMUNITY SUPPORTS PROGRAM SERVICE DEFINITIONS

Assistive Technology and Supports (ATS)

ATS includes devices, controls, or appliances that enable individuals to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment they live in, thus decreasing their need for assistance from others. Approvable items are limited to those necessary to support individuals in their home and must be appropriate to the needs of the individual as a result of limitations due to disability.

Community Living and Day Supports (CLDS)

Community Living and Day Supports provides the necessary assistance and supports to meet the daily needs of the individual. CLDS includes the following components:

- Assistance with hygiene, bathing, eating, dressing, grooming, toileting, menstrual care, transferring, or basic first aid.
- Supervision and monitoring for the purpose of ensuring the individual's health and safety.
- Supports to enable the individual to access the community. This may include someone hired to accompany and support the individual in all types of community settings.
- Supports to assist the individual to develop self-advocacy skills, exercise rights as a citizen, and acquire skills needed to exercise control and responsibility over other support services.
- Supports to assist the individual in identifying and sustaining a personal support network of family, friends, and associates.
- Household activities necessary to maintain a home living environment on a day-to-day basis, such as meal preparation, shopping, cleaning, and laundry.
- Home maintenance activities needed to maintain the home in a clean, sanitary, and safe environment. This may include heavy household chores such as washing floors, windows and walls, tacking down loose rugs and tiles, or moving heavy items of furniture.
- Supports to enable the individual to maintain or obtain employment. This may include someone hired to accompany and support the individual in an integrated work setting. Integrated settings are those considered as available to all members of the community. Payment for the work performed by the individual is the responsibility of the employer.

Covered services do not include those provided in specialized developmental disability provider-operated settings, work stations, or supported employment services.

- Supports to enable the individual to access services and opportunities available in community settings. This may include accessing general community activities, performing community volunteer work, and accessing services provided in community settings such as senior centers and adult day centers. Assistance with personal care needs or household activities is available only to those individuals who do not live with a paid caregiver. A paid caregiver is an individual or agency paid to provide services to meet the individual's daily needs. This does not include payments made for room and board.

The Community Living and Day Supports service is intended to provide necessary supports for the individual, but is not intended to duplicate or replace other supports available to the individual. Transportation to and from community activities is not covered as a separate component under this service. Fees, membership costs, and equipment costs related to social, leisure, and recreational outings are not covered under this service.

Home Modifications

Home Modifications are those physical adaptations to the individual's home that are necessary to ensure the health, welfare, and safety of the individual, and/or which enable the individual to function with greater independence in the home. Examples of approvable modifications include:

1. Installing ramps, lifts, door levers, and grab-bars;
2. Building an accessible entrance into the home;
3. Widening interior doors to provide accessible routes of travel within the home to the bedroom, bathroom, and kitchen;
4. Modifying existing bathrooms to add roll-in showers, raised toilets, roll-under sinks; and
5. Adapting electric and plumbing systems to support assistive equipment, such as chair lifts and bathroom facilities.

Approvable modifications do not include adaptations or improvements to the home that are of general utility, and are not of direct medical or remedial benefit to the individual. Examples of home modifications that may not be approved include:

1. Home maintenance and repair such as carpeting or roof repair;
2. Access to the basement for use as a storm shelter or recreation;
3. Recreational pools and decks;
4. Remodeling not related to accessibility or disability-related needs;
5. New construction (exception may be made where a bathroom cannot be made accessible);
6. Restrictive modifications that replace supervision, such as half-doors, fences, and security items. Items which assist in supervision and are specifically related to the individual's needs due to disability may be considered, if necessary to ensure safety;
7. Central air conditioning; and
8. Adaptations which add to the total square footage of the home.

Personal Emergency Response Systems (PERS)

PERS is an electronic device which enables individuals to secure help in an emergency. The individual may also wear a portable "help" button to allow for mobility. The system is connected to the person's phone and programmed to signal a response center once a "help" button is activated. PERS services are limited to those individuals who live alone or who are alone for significant parts of the day and have no regular caregiver for extended periods of time, and who would otherwise require extensive routine supervision.

Respite

Respite is the temporary, occasional relief to the family from the continuous support and care of the individual. This service is available only to those who live with the usual non-paid caregiver(s). The term "usual non-paid caregiver" means a person who resides with the individual, is not paid to provide services, and is responsible on a 24-hour per day basis for the care and supervision of the individual. This service cannot be provided by members of the individual's immediate household. This may be provided in the individual's home or community.

Vehicle Modifications

Modifications to vehicles may be made for purposes of accessibility when the vehicle is privately owned by the individual or his/her family and is used to meet the individual's transportation needs. The vehicle must be in good operating condition and modifications must be made in accordance with applicable standards of manufacturing, design, and installation.

Source: CSP Consumer Handbook

APPENDIX C. PROVIDERS' INPUT

To: LR 156 Committee
From: Dave Merrill, other providers on the LR 156 Committee
Date: October 17, 2008
Re: Funding Methodology and the Waiting List

Overview of funding methodology and the interaction with the waiting list.

It is clear that the funding methodology and the practices adopted by HHS directly affect the capacity of the system to recruit and retain qualified staff to provide supports to address the waiting list. In addition, the funding system has a major impact on the capacity of the system to be flexible to the changing lives of people receiving supports. We have provided some basic points to consider about the funding methodology and practices that are relevant to the waiting list.

- * The basic premise of the funding methodology and intervention unit system was to provide "portability" so people could choose any provider and have the money follow the person.
- * People with higher need levels receive greater support; the hope was to provide "no more, no less" than what a person needs.
- * Consistency is achieved by an Objective Assessment Process (OAP) using the ICAP assessment to determine the number of intervention units. It is important to use the term "units" rather than "hours" because according to people in the department at the time of development there was never an intent to apply the "face to face" criteria to assisted residential services. All providers are reimbursed at the same rates for the same services. How well this works can be questioned, but it is a consistent process. It should also be noted that the OAP has not been implemented for hundreds of people who were "grandfathered" into the system when it was implemented for new people entering the system several years ago.
- * The Medicaid Waiver provides 59.54% federal and the state provides 40.46% of the funds when a person is served under the Waiver. Since not everyone is on the Waiver, it is about a 50/50 split for overall services. We should ensure that when people are authorized for services they go on the Waiver immediately to maximize federal funding.
- * The funding methodology is based on 90% of an entry salary for a position (Tech 1) at Beatrice State Developmental Center that is paid to part time and temporary employees at BSDC. It should be based on the average salary of a Tech II position, since these are full time employees at the direct support level.
- * Current rates under the methodology are much lower than the 90% due to recent salary increases at BSDC. The major increased costs in human services have been in the area of benefits, due to increased cost of health insurance, worker's compensation insurance and other benefits. Benefits originally computed at 20% of salary in the model are closer to 40% today.
- * The funding methodology has not been adapted for higher transportation costs, medical services support, issues around "sleep time" and increased regulation. In addition, there are issues regarding reimbursement for staff time in group homes for overnight coverage. There

are also higher costs for certifying medication aides and licensing of residential settings that have not resulted in increases in rates.

While there are many issues concerning the funding methodology and practices that affect the waiting list, we have focused on three primary factors; adequacy, flexibility, and accountability.

Adequacy

While it is clear that money is not the only barrier to staff recruitment and retention, it is perhaps the most critical factor.

The funding methodology was based on 90% of an entry level salary of a position at BSDC that is now rarely used because of an inability to recruit. The State billed the Federal government at 100% of the methodology but paid providers at 90% of the methodology. (They argued that providers came up with the other 10% on their own.) Recognizing that this was not happening, they began billing the Feds at the 90% rate they were paying us, effectively lowering the methodology by 10%.

There are two references to 90% that may be confusing. The rate was built on 90% of the salary of the Tech I with the idea that the state would be paying providers less than they pay their own employees. Then the state said that 10% of the methodology amount was being provided by county funds and other sources so they would only fund 90% of the methodology rate.

In addition, recent salary increases at BSDC have caused providers to fall even farther below the 90% level. Funding should also be based on the average Tech II salary, not entry level of Tech I. We must recruit and retain quality staff.

The methodology was developed to support people with DD through habilitation. The people supported today have broader needs than the funding for habilitation envisioned.

Recommendation: Restore the methodology to the 100% level and fully fund it. Modify the methodology to reflect the average Tech II's salary and the current percentage of salary to benefits. Do not return unused money to the general fund, but apply it to the waiting list.

Flexible Funding

The current system of intervention hours does not have the flexibility to respond to changes in individuals' lives due to health issues, behavioral issues, seasonal changes and family situations. Because the State of Nebraska cannot afford to provide one-to-one supports for everyone who needs staff available at all times, we provide some support in groups that demand flexibility of funding.

The current system offers a method, while less than ideal, to develop a more flexible method to address individual needs. It is proposed to multiply the rates by the approved hours to develop a monthly rate for the supports provided to an individual.

Due to the congregate nature of supports, when an individual dies or leaves the system out of an assisted residential setting (group home), a compatible roommate from the extensive waiting list should be found, rather than forcing remaining roommates to move in order to match them with other people simply to have enough hours to provide 24/7 staffing. This does not apply when a person chooses another provider and takes their funding with them. We do not intend to promote group homes as the best choice for people, we simply recognize we may not be able to provide one-to-one support to everyone who needs 24/7 supports.

Recommendation:

- 1. Develop a monthly rate for assisted services. (These are services where staff are always available.)**
- 2. Develop a waiting list priority system that enhances capacity.**

Accountability

It is important to the Nebraska tax payer and all of us as stewards to provide accountability for the use of public funds. It is an equally important facet of stewardship to develop processes that are efficient and effective in delivering outcomes that are desired by the people we support and their families.

While the State reimburses for each individual, they recognize the need for using staff effectively and the number of hours are based on a number of individuals receiving support at the same time.

Accountability should focus on the person receiving supports rather than the staff and billing system. The state should become a partner in developing innovative, efficient, and effective methods of delivering the outcomes that people want and need.

Recommendation: Use service coordination monitoring reports, quality review teams, certification processes, critical incident reporting, family involvement, etc. to determine whether the supports have been provided in accordance with the Individual Program Plan. Audits should measure outcomes for people rather than whether staff was present.

Implement electronic billing and reimbursement to reduce errors and provide easier tracking.

White Paper on the Status of Developmental Disability Services in Nebraska

June 30, 2008

Number of people needing support as of June 30, 2008

* There are approximately 4,567 people receiving specialized developmental disability services in the community and 270 people residing in state institutions at Beatrice State Developmental Center and the Bridges program in Hastings. There are also 239 people living in three private ICF-MRs in Beatrice, Axtell, and Grand Island.

* There are 2799 people on a registry waiting for services across the state now or sometime in the future. Of those, 1,868 are past their requested date of need or have requested services by June 2008. Some people on the list have been waiting since January of 2003. The decision by several HHSS administrations to only fund day services for graduates has contributed to the waiting list.

* It is difficult to estimate the number of people who are not receiving services and are not on the registry.

Additional Information

* Nebraska uses "means testing" to determine fees for individuals or families with minor children based upon financial ability to pay. These fees are collected by HHS.

* HHS determines eligibility and funding for each individual, the individual and their family choose his/her provider. The person's funding follows the person if he/she chooses another provider.

* The Medicaid Waiver provides a match for Medicaid waiver eligible people in the system. The match is 59.54 percent Federal, 40.46 percent state and local. These funds have provided the bulk of increases to the system over the last decade.

* Providers are required to provide documentation of habilitation and must meet specified service needs that are driven by an Individual Program Plan (IPP).

* Accountability is provided by a system of certification, regulation, complaint investigation, service coordination monitoring as well as oversight by local boards and advisory committees, advocacy groups and consumer satisfaction surveys.

* Fiscal accountability is provided by statute and regulation.

Issues needing attention by the administration and legislature.

* Waiting list - There needs to be a plan to address the waiting list in a systematic way. There are several approaches that can be taken but we must have a measurable way of determining whether we are making progress, two possible measures include the length of the

waiting period or the percentage of eligible people served. The Developmental Disability Services Act stated the intent to address the waiting list but money has not been appropriated. In addition, the Federally mandated agency, Nebraska Advocacy Services has a current lawsuit against the state for the long waiting period and method of determining the amount of money allotted for each individual.

* The funding methodology is based on 90% of a salary at Beatrice State Developmental Center that is not used as a base salary because of an inability to recruit staff into that position. With recent salary increases at BSDC current rates are much lower than the 90%. The major increased costs in human services have been in the area of benefits due to increased cost of health insurance and training to maintain a competitive wage to attract and retain qualified professional staff.

* The basic assumptions of the funding methodology need to be examined. Changes in the last 14 years include increased transportation costs, medical services support, sleep time and increased regulation. The support needs of person receiving services have increased due to changes in eligibility criteria. In addition, benefits originally computed at 20% of salary in the model are closer to 40% today.

* While the funding methodology is complex, the basic concept is that whatever percent increase state employees receive at BSDC should be provided to community based providers. Community providers face all the same issues of increased cost of insurance, difficulty in recruiting and retaining staff and increased demands through regulatory agencies. It still costs the state significantly less than if state employees were to provide the supports.

* There needs to be a clearly understandable and fair way to determine the amount of support that the state will provide to an individual. While there is no perfect Objective Assessment Process (OAP), we need to agree on an effective assessment process that is flexible and changes with the needs of the individual.

* Quality needs to be defined by people supported and families, as well as officials.

* We need to remove the requirement for an elected official to be on the boards or advisory committee of certified providers. Public agencies are governed by county commissioners and need no additional representation on the advisory committee that has only the power to make recommendations. Private agencies find it cumbersome and ineffective to recruit an elected official.

Brief History

Prior to the late 1960's, mental retardation was the term used to describe individuals with significant learning disabilities and the only option to families was the Beatrice State Home which is now called the Beatrice State Developmental Center (BSDC). The population at BSDC grew to over 2200 people and an investigation and federal lawsuit (Horacek vs. Exon) led to the growth of community services.

The state established 6 regions from Region I in the Panhandle to Region VI in the Omaha area. Governed by boards of county commissioners from each of the respective areas, they provided options for families across the state. In addition, Martin Luther Home and Bethphage Mission expanded their options from ICF-MRs, (small private institutions) to community based options. At approximately the same time, a change in the laws governing special education occurred, giving families the option of having their children remain in the community and receive an appropriate education.

The State of Nebraska has historically respected the views of family members in determining whether they will receive supports in an institution or the community and that remains true today.

In the past decade the number of certified providers has expanded to include over 30 different providers giving people with disabilities and their families significant choice of providers while retaining efficiency and the option of public community supports.

Acronyms

AAIDD - American Association on Intellectual and Developmental Disabilities - (A national organization with a Nebraska chapter focusing on research, best practice, and professional networking.)

ACP - Association of Community Professionals - (An organization for people who work in the field of developmental disabilities.)

The Arc of Nebraska - (An advocacy organization for people who experience developmental disabilities and their families. It has local, state, and national affiliation.)

DDD - Division of Developmental Disabilities - (Division of HHSS devoted to specialized services for people with developmental disabilities.)

HHSS - Health and Human Service System - (State of Nebraska organization for human services)

NAS - Nebraska Advocacy Services - (A federally mandated advocacy organization.)

NASP - Nebraska Association of Service Providers - (An association of providers affiliated with the national organization American Network of Community Options and Resources, ANCOR)

NPN - Nebraska Providers' Network - (A voluntary association of Nebraska public and private providers with no fees or staff.)

PFN - People First of Nebraska - (Self Advocacy group originating in Nebraska, now international.)

Chronology

1950s - Families begin to form programs to support their family members to fill the void between sending their children to Beatrice State Home and the lack of special education in the

school system and other supports in the community. In 1968, the Douglas County Plan formalizes this "grass roots" family movement.

July 1969 - LB 855 transfers the Office of Mental Retardation to the Department of Public Institutions from the Health Department moving away from a medical model.

1972 - The Horacek vs. Exon federal civil rights class action lawsuit is filed against the State of Nebraska. Due to this lawsuit, the population of the Beatrice State Home is reduced and the legislature appropriates funds for the development of community services and deinstitutionalization.

May 1973 - LB311 creates the six mental retardation regions in Nebraska, modified by LB302 in April 1974.

1974-1975 - Regions form governing boards of county commissioners. Advocacy groups feel county commissioners are able to offer local control and accountability and that public services are necessary to assure that low population areas of the state are adequately served.

Fall 1987 - Nebraska implements the Medicaid Waiver, capturing available Federal funds to supplement the State General Funds that had funded the system.

1991 - LB 830, the Developmental Disabilities Services Act is passed. After a study and much discussion, provider based case management services is transferred to state administered Service Coordination. It also transfers responsibility for waiting lists to the State of Nebraska, the state must authorize and approve funding prior to placement for a provider in order to receive state and Federal funding. In addition the federal definition of developmental disability is adopted, expanding the definition from the narrower mental retardation category.

1994 - LB 1136 provides additional funding to serve people in the community waiting for funding.

June 1995 - The Governor's Blueprint for Action contains a plan for eliminating the waiting list by requiring HHS to submit a plan to see that people leaving high school are offered supports, HHS interprets this to cover just day services so the waiting list continues to grow.

1996 - Medical service supports transfers back to providers from service coordination.

1998 - Administration and supervision of service coordination transfers from developmental disability Services (DDS) to the Health and Human Service System (HHSS) service areas.

APPENDIX D. STATES' WAITING LIST INITIATIVES

Annual Program Performance Report of State Councils on Developmental Disabilities 2007 Waiting List Narratives

AK

In conjunction with Senior and Disabilities Services and other stakeholders, the Council has been working to redesign the process by which people are drawn for home and community based services. An Ad Hoc Committee was formed to develop a new tool for determining placement on the wait list, and a new scoring system. The new tool was piloted at one urban and one rural provider agency during the last fiscal year, and the State began using the tool in the fall of 2007. The pilot demonstrated that the new tool is effective and improves the process and method by which people are drawn from the wait list. In addition, the group recommended numerous process improvement and recommendations for a tiered service delivery system were developed.

On September 30, 2007 there were 1,301 individuals on the wait list for services. After several years of flat funding for DD services, 136 people were drawn for services in FY07. Two groups of individuals were targeted, those over 40 years of age and who were likely living with aging caregivers, and those between 22 and 28 years of age, and who were transitioning from school to work. Of those, approximately 100 were interested, eligible, and have either begun receiving services, or are in process. Senior & Disabilities Services is committed to drawing 50 individuals per quarter doubling the number of recent annual draws, with the intent of eliminating the wait list or at a minimum, better managing the wait list so individuals and families don't wait more than a few months for services. The Alaska Housing Finance Corporation (AHFC) maintains a waiting list for Section 8 vouchers. Unfortunately, the process used to determine the number of people with disabilities waiting for services has been inconsistent over the past few years. Based on available information this year, AHFC estimates that number of people with developmental disabilities waiting for housing vouchers increased by 12 percent.

AL

Alabama continues to work at addressing the needs of persons on its waiting lists and to make it possible for people to access home and community-based services within a service system that is moving toward consumer driven/ person directed services. Currently there are 1743 persons waiting for services on the Waiting list. This number includes those waiting for services through the MR Waiver as well as the Living at Home Waiver. In FY 07, Alabama Department of Mental Health and Mental Retardation was able to serve 622 persons from the waiting list and provided 834 different services (279 residential, 319 day, and 236 supports). The division of Mental Retardation continues to manage the waiting list and prioritizes people based on assessment of the severity of their needs and the length of time waiting for services.

AS

During the fiscal year 2007 (October 1, 2006 to September 30, 2007), three requests came to the DD Council from families of children with disabilities to be housed at the Respite Care Center. Because of the limited space available at the Center, only one was accommodated. Two more are still on the waiting list.

AZ

The Arizona Department of Economic Security, Division of Developmental Disabilities (DDD) pulls wait list data from its management information system which identifies individuals waiting for one or more services by age (segregated by those over and under age 18). The wait list numbers reflect the number of people whose name appeared on the waitlist for one or more services for the timeframe October 1, 2006 through September 30, 2007. The wait list includes: 1) individuals who are unserved or underserved and are eligible for services provided through the long term system (Medicaid). Waiting for a service does not mean individuals are not receiving services; Medicaid-eligible individuals may be waiting for one or more services that are more difficult to obtain, including specialized services and/or services from a specific provider. An alternative service may be provided while the individual waits for a specific service and/or provider. Waitlist activity summaries generated from the Division's management information system report the number of individuals waiting for one or more services by age (segregated by those over and under age 19). Medicaid adults (Vocational) referred to Rehabilitative

Service Agency are not included in this count. The number of individuals waiting for one or more services is derived from reports for the requested timeframe. The waiting list is in constant flux. Barriers to service include limited appropriation for state only consumers and a statewide shortage of physical, occupational and speech therapists. The Division takes action to decrease the waiting list numbers by developing a network plan to address gaps in service throughout the state, rate increases for therapists and recruitment strategies to encourage development of rural therapy providers.

CA

There have been no changes to the information previously submitted.

CO

The demand for dd services is growing much faster than population growth and the State's ability to add new resources. The growth is tied in part to the baby boom cohort of persons with dd. This group increasingly requires state-funded services as their parents age. While Colorado is ranked 48th for fiscal effort for dd services, Colorado's dd service penetration and expenditures per person served are not far from the national average. Recent funding has targeted individuals transitioning from foster-care (who are not generally included on waiting lists); emergencies, based on current or imminent homelessness, an abusive or neglectful situation place the person's health, safety or well being in serious jeopardy, are a danger to others or a danger to self and the high risk persons that include 40 or older and living at home with parents or relatives, have a condition like dual diagnosis including mental illness, significant behavioral problems, non-mobile and/or medically fragile and those who have a functioning level of profound indicating a nearly constant level of daily care needs. One area that Colorado continues to struggle with is if there was enough funding in the system to cover the waiting list, would there be capacity. The interim committee heard testimony that low direct support staff wages, competing industries and high turnover make capacity an important correlated discussion with the Wait List. Recent surges in oil and gas exploration and development have created an even greater abyss for capacity in the rural reaches of Colorado. A coalition of advocates is exploring the potential for a targeted ballot measure for a sales tax increase to fully fund the existing wait list. A group of legislators that served on the summer interim committee have proposed a bill that would create a developmental disabilities cash fund with over 8 million dollars, growing each year incrementally and having the potential to roll over. With the pent up budget demand due to TABOR, Mental Health, Higher Education, Transportation and Education all have compelling needs that will no doubt tax the political will of the legislature, the executive branch and all Coloradans in setting funding priorities. The transformation of waived services into CMS₂ template and the expectation for Consumer Directed Services to be incorporated into the Comprehensive Service and Supported Living Service Waivers are all likely to have some impact on future wait lists.

CT

1. DMR's FY 2007 Appropriation funds \$4.1 million for the annualization of residential and enhanced family support, and Rent Subsidy Wait List placements, that were made in FY 2006, plus \$4.6 million to fund 150 new residential and 100 enhanced family support, and new Rent Subsidy Wait List placements, in FY 2007. The department's request for both annualization of services and new funding for services was included in new appropriations. 725 people were on the department's waiting list for residential services and 228 for day services. Appropriations provide for 66 people for residential services in FY 08 and 64 in FY 09, 79 for day services in FY 08 and 73 in FY 09, and 270 high school graduates in FY 08 and 245 in FY 09. There were also 192 people receiving services who were waiting for additional services plus 54 people in LTCs waiting for a service 2. Expansion of the KB waiver is allowable to 200 children. The Katie Beckett waiver was funded fully with 200 slots. The Council testified for additional appropriations. 3. 560 people are on the PCA waiver. State legislation enabled the expansion of the waiver to reach 698 people. New funds for additional people was appropriated for FY 08 and FY 09 but will reach only about 70 people each year. The Council testified for additional appropriations. 4. The Birth To Three list changes daily. The existence of a "waiting list" is disputed by the system but is generally known in practice. Appropriations fund expansion for eligible babies with very low birth weight, babies born at fewer than 28 weeks, children with significant delays in speech and biological risk factors and children with mild or unilateral hearing loss. 5. Since the start of the SNF Transition Project in June 2002, 311 people sought to transition. 127 have transitioned to the community. \$8.4 million was appropriated to implement a Money Follows the Person demonstration and increases from 100 to 700 the number of individuals to be served over a 5 year period. The Council testified for additional appropriations.

NOTE: States are now allowed to cover HCBS as a Medicaid State Plan option for certain individuals without requiring the person to prove that institutionalization would be the alternative. States may limit the number of people who can participate in this benefit AND ESTABLISH WAITING LISTS.

DC

The District of Columbia does not have waiting lists in its principle State Agencies responsible for service delivery to individuals with developmental disabilities.

DE

The DDDS Registry is a crisis based list that categorizes people by crisis severity and services are delivered based on that rating. Case Management services are offered to all clients of that Division. The DSAAPD Wait List was cleared this fiscal year with additional funds from the General Assembly with tobacco funds.

FL

The number of individuals with developmental disabilities on Florida's Waiting List for services under the Agency for Persons with Disabilities (APD) continues to grow, despite reports of over 900 people being newly enrolled in waiver services between October 2006 and September 2007. In October 2006, approximately 19,400 people were on the waiting list. Of this number, about one-third of the individuals (N=6,588) were served in the Family Supported Living Waiver (FSL) while waiting for services under the Home and Community Based Services Waiver (HCBS); one-third of the group (N=6,799) were receiving some type of state services such as state plan or pharmacy services; and about one-third of those waiting (N=6,083) were receiving no services. At the end of the reporting period and the most recent data available (October 1, 2007), the number of people on the Waiting List had increased by over 2,250 to 21,728. The status of those on the Waiting List includes 28 percent of the group (N=6,080) served in the Family Supported Living Waiver (FSL) while waiting for services under the Home and Community Based Services Waiver (HCBS); 36 percent (N=7,840) of those waiting were receiving some type of state services such as state plan or pharmacy services; and 36 percent of the group (N=7,808) were receiving no services. The number of people waiting for services and receiving no state services has grown from 6,083 at the beginning of the reporting period to 7,808 one year later, an increase of 1,725. Of the more than 15,000 individuals reportedly on the Waiting List as of October 1, 2007, excluding those enrolled in the FSL waiver, 30 percent of the group (N=4,741) have been waiting for 48 months and longer; 17 percent (N=2,770) have been waiting 36 to 48 months; 15 percent (N=2,316) have been waiting 24 to 36 months; 19 percent (N=2,995) have been waiting 12 to 24 months; and 19 percent (3,035) have been waiting for up to 12 months.

One potential avenue to increase access to needed services for those on the Waiting List has been a renewed emphasis on the use of state plan services and, in particular for children, access to services through the Early and Periodic Screening, Diagnosis and Treatment of Children (EPSDT). The most recent data available (9/1/06) on individuals on the Waiting List by age indicates approximately 60% are aged 3 to 21 years.

GA

The Legislature funded 1500 waiver services against the 2000 recommended by the multi-year funding plan, but expresses concern about the legitimacy of how the Division of MHDDAD tracks progress on the waiting list funding. In response, advocates have begun conversations with the Division about useful indicators that will record consistent progress from year to year. Advocates estimate that the waiting list grows by 1100 individuals each year, due to three primary reasons; population moving into the state, students graduating from high school, and people needing to move from their parents or caretakers homes because the care givers are aging or become disabled.

For the CCSP population (senior / disabled) the non-Medicaid waiting list has burgeoned due to individuals dropping off the Medicaid list because of the Estate Recovery practices put into effect. For the ICWP waiting list, 52 reflects the number of slots that the Georgia Advocacy Office reported this year, however, advocates are pressing for 500 slots, which more accurately reflects individuals identified in nursing homes who are appropriate, and desire transition to the community. Keeping a more accurate count of the need for ICWP services has become one of the priorities for the Unlock campaign.

HI

As a result of the settlement agreement in Makin II lawsuit initiated by Hawaii Disability Rights Center, there is currently no waiting list for services.

IA

The disability service delivery system in Iowa remains complex and fragmented with waiting lists that are inconsistently maintained or defined and which may not truly reflect unmet need. The state funds most services to children and partners with counties to fund services to adults (services to persons with MR and CMI are mandated). The locus of control rests with the counties who manage the funding and delivery of most adult services, including those provided through the HCBS/MR waiver. The state imposes few requirements on counties and the resulting inconsistencies and inequities extend to include waiting lists. Eligibility for services and the array of services varies among counties, as do county determinations about whether to maintain waiting lists for services or supports. Counties report who is being served with what services but do not report consistent information about waiting lists. New system improvements initiatives are exploring options to equalize access and reporting and to obtain and interpret statewide information. The state does maintain waiting lists for Medicaid HCBS waivers for which they pay the nonfederal share. On September 30, 2007 those lists had grown to 2,700 individuals among the state's seven waivers, with an average wait time for the Ill and Handicapped and Physical Disability waivers of just over one year. The 2007 Legislature did appropriate an additional \$2.2 million to reduce the waiting list for the Children's Mental Health Services Waiver but no new funds were appropriated to the state's other six waivers. Individuals who apply for services through Iowa Vocational Rehabilitation Services (IVRS) and are determined eligible are placed on one of three waiting lists: 1) Most Significantly Disabled (MSD), 2) Significantly Disabled (SD), and 3) Others Eligible. All individuals who are considered Most Significantly Disabled must be served before those on the Significantly Disabled list, and individuals on both the Most Significantly Disabled and Significantly Disabled must be served before those on the Others Eligible list. As of November 13 2007, IVRS had cleared the MSD and SD waiting lists through that date. Additionally, persons identified as Others Eligible through June 30, 2003 were cleared from the waiting list. Approximately 600 individuals remain on the Others Eligible list. Each month IVRS considers the number of individuals the agency has the capacity to serve, and serves those at the top of the list.

ID

The number of people awaiting extended employment services reduced from 250 to 153. This 39% reduction in the number of individuals awaiting services is reflective of program management practices by the Division of Vocational Rehabilitation. Administrative control of these services was transferred to the Division in 2004. The Division has given high priority to ensuring that all allocated funds are distributed to service providers. In turn service providers maintain full enrollments by moving people from waiting lists.

A price is being paid for the Division's financial efficiency. The individual budgeting process that is portable and allows individuals to select their choice of providers has disappeared. Individuals on waiting lists are required to select providers with available budget even though it may not be their choice of providers. While budgets are assigned to an individual, it does not follow the individual should there be a desire to change providers. A cadre of long term providers has greatly influenced these practices and new providers have experienced difficulty in acquiring funding.

During the 2007 legislative session the Division of Vocational Rehabilitation sought approval for rules that would have greatly restricted new providers from the service arena. The Council and its partners successfully argued against those restrictive sections resulting in 7 new providers being approved by the Division. The Division continued to address other points of contention by conducting two stakeholder meetings which resulted in much dialogue and no action to alter any Division administrative practices.

Finally the Division of Vocational Rehabilitation submitted a \$500,000 budget increase to allow individuals on the two waiting lists to be served. The Council reviewed the proposal and supported the increase in funding but limited its support for funding to serve only individuals awaiting supported employment. The Councils support was consistent with its segregated employment position statement. The request will be considered by the 2008 Idaho Legislature which begins January 7.

IL

P.A. 93-0503 required the Department of Human Services to compile and maintain a cross-disability database of Illinois residents with a disability who are potentially in need of disability services the department including those transitioning from special education. Nov. 1, 2004 was the launch of the IL PUNS system, which is a data collection process to determine needs. 11,800 individuals/family members have completed a PUNS as of December 4, 2007.

IN

Autism/ Developmental Disabilities were combined in 06 reporting but separated in 07. The AL list is no longer maintained since AL services have been folded into the A&D waiver.

KS

Small reductions (6%) in DD Waiting lists. The Legislative Interim Budget Committee recommended a 3 year phase in of WL reduction funds but it was not adopted during the Session. Increased funding was provided to decrease numbers but not a significant amount. A small rate increase for services was also provided. We are concerned that so many people wait for services, jeopardizing their safety, health and welfare. We plan a significant push for services in FFY08 to do a 3 year phase in of increased funds for services and rate increases to enlarge Kansas capacity. Our hope is that this or a version will be passed and we will have much larger decreases to our waiting lists.

KY

Only one waiting list exists in Kentucky for individuals with mental retardation and developmental disabilities. Although Regional Comprehensive Care Centers may retain a list for their specific purposes. Anyone can make application by submitting a completed application form that includes the signature of a physician or SCL,MRP confirming the diagnosis of mental retardation/intellectual and developmental disability along with

supporting documentation. Individuals are placed on a waiting list by date of receipt of their complete application and by category of need for support services. The Division of Mental Retardation who is under contract with the Department of Medicaid Services for the management of the Supports for Community Living (SCL) Waiver maintains the waiting list. When funding becomes available the applicant will go through an eligibility or Level of Care review for admission to the waiver. Kentucky Medicaid contracts with a Peer Review Organization (PRO) to conduct the eligibility test. Once the person is deemed eligible they should receive services within sixty days. Advocates continue to lobby legislators for increased funding. The continued growth in the number of individuals applying and being placed on the SCL Waiting List can be attributed to the notoriety brought by HB144. An additional 100 slots were appropriated in FY 07 bringing the total allocations available to 3301.

LA

Numbers for the NOW and Supports Waiver are current as of May 2007; OCDD & OMH Cash Subsidy, Elderly & Disabled Adult Waiver, and Adult Day Health Care numbers are current as of June 2007. As of Dec. 2006, Voc. Rehab. has no waiting list. Waiting list numbers for Children's Choice (a capped waiver limited to children) is combined with the NOW registry. 4,814 people on the NOW registry are simultaneously waiting for Children's Choice.

The decrease in the NOW registry is likely due to efforts by the Dept. of Health & Hospitals to validate the waiting list and may reflect a decrease in the state's population. Increased funding for NOW services passed by the State Legislature this year is expected to result in a decrease in the number of people waiting for this service. However, those funds would not have been implemented at the time the current waiting list number was reported in June 2007.

MD

DD Community Services Waiting List: The waiting list for community DD services has grown to 16,820 people \hat{c} nearly an increase of 1000 people over the past year. Individuals on the list are requesting over 30,000 services (residential, day and/or support services). 94% of them need at least one service now \hat{c} they are in the priority categories: crisis resolution, crisis prevention, or current request. 51% of the services requests fall in a \hat{c} crisis \hat{c} category. Over 11,500 people on the list are not receiving any services. The others receive some services and are waiting for additional types of services. _Only 6% of the people are on the list as \hat{c} Future Need. \hat{c} The need for services grew in all parts of the state, with the growth ranging from 23%-200%. Funding was provided for approx. 600 transitioning youth, but other than that, there has been virtually no new funding. Some people on the WL are served when funds become available due to someone else leaving service. This is a relatively small number compared to the vast need.

The autism waiver has 900 children enrolled and 1236 on a waiting list. People get on the waiting list before eligibility is determined. Experience shows that approximately 60% on the waiting list will be determined for the autism waiver.

Section 8 Housing: WLs for Sect. 8 rental vouchers vary thru out MD and no jurisdiction reports intellectual and developmental disability specific data. Sect 8 waiting lists, in general continue to grow as need outpaces the availability of vouchers and national policy reduces the number of vouchers available to local jurisdictions. Maryland has implemented the second year of a pilot project that provides temporary

rental assistance specifically for people with disabilities (Bridge Subsidy) to address a very small part of the need.

ME

The waiting list for Vocational Rehabilitation services has been reduced by almost 40 percent from FFY05. Individuals receiving VR services are all in the category #1 classification (most significant disabilities). Their wait time on the waiting list has also been reduced from an average of 10 months in the previous year, to less than 4½ months by the end of FFY06. Individuals in categories #2 and #3 (significantly disabled, disabled) are not receiving services at this time. A continuing problem for category #1 VR clients is the lack of available funding for long-term job supports. (A pending Medicaid waiver request may improve this situation in the coming months.) Until then, any VR client whose employment plan indicates he/she will need long-term job supports does not receive further VR services due to the lack of funding.

Children with DD who do not meet medical eligibility criteria for the mental retardation/autism waiver and have not been identified as having mental health problems (with cerebral palsy, epilepsy, spina bifida, etc.) are not included in any waiting list, so the unmet needs of these children and their families, such as respite care, are not reflected in the lists.

The adult services waiver programs continue to be closed. The waiver for adults with mental retardation/autism is adding only individuals who are in Adult Protective Services status, usually due to the death/ill health of family caregivers. The waiting list of 117 is not in priority order persons ranked anywhere from 1 to 117 on the list may be moved onto the waiver program because their needs reach APS status. Other individuals will be put onto the waiver program due to emergent needs, without having been on the waiting list.

The consumer-directed physical disabilities waiver program, which provides funding for community services for individuals age 19-64, has been closed for many months, due to funding problems. The waiting list does not include individuals who need more service hours per week than the maximum authorized under the waiver at this time; those individuals have been forced to move into nursing homes rather than stay in the community. Some individuals are also forced into nursing homes because they cannot find in-home support services to meet their needs, due to the severe shortage of direct care workers in Maine. This population is also not reflected in waiting list numbers.

MI

DD Institutions: As of September 30, 2007, 115 persons with intellectual and developmental disability are in Mt. Pleasant, the state's sole institution for this population. This number is less than that of past years because the MI Department of Community Health is working to reduce the number of persons with developmental disabilities in the ICFMR by both working to transition current residents back to the community, and to reduce the number of new admissions. The Community Mental Health System is working to develop the capability and capacity of local providers to provide behavioral supports and crisis prevention/response to individuals with a intellectual and developmental disability. Additionally, MDCH has created

a virtual team to review cases of persons at risk of admission. They usually have problem behaviors. Another factor is that advocacy from disability groups has exerted pressure to close and/or reform the institution, and media has focused on allegations of abuse and neglect, including a suspicious death in a prior year, which is still being investigated.

Section 8 Housing:

976 is the waiting list number for vouchers currently, since the previous year was only 324, it has more than tripled. The likely reasons for the increase are Michigan's continuing economic problems and a substantial reduction in federal funding for Section 8.

MN

A total of 14,624 individuals are receiving services under the DD waiver (compared with 14,963 in FFY 2005 and 14,824 in FFY 2006); 313 individuals under the CAC waiver (compared with 245 in FFY 2005 and 276 in FFY 2006); 12,881 individuals under the CADI waiver (compared with 10,101 in FFY 2005 and 11,372 in FFY 2006); and 1,455 individuals under the TBI waiver (compared with 1,206 in FFY 2005 and 1,349 in FFY 2006).

During the past four years, the Minnesota legislature set limits on the number of people who could enroll in the CADI and TBI waiver programs. As of July 1, 2007, these waiver programs are available to all eligible individuals. First consideration will be given to individuals waiting for services and those under age 65 in institutional settings.

A total of 5,183 people are on the waiting list/in need of DD waiver services. Of this total, 285 people are living in ICFs/MR - all are receiving case management services, 5 people are receiving home care services, 1 person is receiving respite, 243 people are receiving day program services, 4 people are receiving job training services, 27 people are receiving education services. A total of 4,290 people are living in the family home, 274 people in foster care, 77 people in their own homes w/up to 24 hrs of supervision, 11 people in board/lodging, 14 people in MN Extended Treatment Options (under civil commitment, determined public safety risk, severe behavior issues), 2 people in nursing homes, 230 people are in other types of living arrangements. These individuals are receiving a range of services that may include case management, home care, consumer support/family support grant, respite, homemaker services, home modifications, SILS, other waiver services (CAC, CADI, TBI), education, day programs, and job training services.

MO

MO has a total of 8748 individuals in the 3 waiver programs; 200 in the Lopez or children's waiver, 1042 in the Home and Community Waiver and 7513 in the Residential Waiver. MRDD tracks those waiting for services, not those waiting for a waiver opening. The waiting list for residential services has decreased over the last year. This is partially due to increased case load growth dollars that helped lower the numbers, but it may also have been influenced by the Division's efforts to encourage providers to support people in their communities and homes. The In-Home services wait list has increased as more individuals and families have been identified who need services and the needs of many individuals on the list have increased. Identifying funds to meet the needs of those on the wait lists is further complicated as 46 of those waiting for residential supports and 52 of those waiting for in-home supports are not currently enrolled in Medicaid. The state recognizes the need to address the increasing needs of individuals and families and has continued to encourage partnerships with counties who have tax levies to provide the match for federal Medicaid dollars, allocating services based on needs, and allowing increased self-direction so individuals can use their limited funding in a manner that is specific to their needs and potentially lower the need for high levels of programmatic types of services. MRDD acknowledges that their current system does not allow individuals to access services prior to reaching a crises situation and is looking at developing a crises facility in St. Louis. However advocates feel that crises services are generally more effective when provided in the home and community. MRDD is also transitioning case management to willing county boards or other providers to decrease the numbers of state FTEs necessary and to lower case load numbers. This may encourage additional county boards to partner with the state to meet the service needs of those in their region. Advocates are concerned about moving to a county based system and even more so by a system in which private entities provide case management, but MO's legislature will not increase state funding for services or FTEs leading the state system to feel this is a viable option. Advocates know that this major system change will guide services for many years to come and that it will be difficult to bring the options from the previous system back once the transition is made.

MS

Changes have been small in number

NC

As we reported in the 5-Year NCCDD State Plan, NC doesn't maintain official waiting list data; however, a current analysis of the NC Support Needs Assessment Profile (NC-SNAP) indicated that 1456 consumers have gone to a LME and were screened for needed services; 205 consumers were receiving some services but needed additional services; and 1190 consumers were waiting for services that were not available. These figures total 2851. While the number does not reflect the total number of persons with ID/DD waiting for services, it is the best data available to us at this time. During this plan year, NCCDD sponsored a forum on waiting list data collection with Celia Feinstein, a national expert on this issue.

ND

North Dakota continues to not maintain formal waiting lists for services to persons with developmental disabilities.

NE

Nebraska has a current waiting list for services from the Intellectual and developmental disability System. As of June

30, 2007 it showed that 1436 people had requested services be provided on that date or earlier. However, several factors must be considered when looking at the waiting list. The list includes

individuals that currently receive a service but may want additional services or hours. People on the list are not evaluated for their eligibility for requested services until they are offered services. Because the list is long, individuals may put their names on the list to be sure they can receive a service when they need it. For example, residential services may be requested in anticipation of a parent not being able to care for the individual. However, when contacted about the availability of the service, the individual and family may turn it down or delay it since their current situation is working well. This is a marked increase in numbers of people on the waiting list from the PPR but it may be the result of when the report was run. Youth completing high school at 21 are entitled to day services in Nebraska. They would be on this registry while those services are being finalized after exiting school in the spring. It is possible that the numbers are slightly inflated in June since these youth may not have begun services yet. Nebraska's Aged and Disabled Waiver does not have a waiting list. It focuses on all people across the lifespan who are at risk for nursing home placement so it serves both children and adults. Vocational Rehabilitation does have an order of selection. Category 2 (those with a significant disability) and Category 1 (those with most significant disabilities) are all being served. Individuals with developmental disabilities would all be included in these two categories so there is no waiting list for them. Category 3 (those with a disability) has not been served for many years and it is unlikely that VocRehab would have the funds to do so. Therefore, no waiting list is maintained for this category.

NH

This past legislative session, a significant increase in funding, resulting from the advocacy efforts of the Council, families and other agencies, resulted in a reduction of the waiting list for developmental services, and a plan to eliminate it in three years. In September 2007 there was a net reduction of 132 people, resulting in the waiting list being reduced to 138 people from 270. At its peak, the wait list grew to over 400 in June of 2003. A legislative committee monitors the waitlist on an ongoing basis. While on the intellectual and developmental disability wait list, individuals are still eligible for other services from DHHS, including Medicaid services for acute care and rehabilitation.

NJ

There currently remains a Community Services Waiting List for placement in community residential settings and a separate Day Program Waiting List for adult day or supported employment served in the order in which their names were added to the lists. People living at home (23,800) often receive only case management services and are waiting for needed programs or supports. Real Life Choices, the self-determination effort in NJ, serves only 500-700 of those 23,800 people. The numbers reported are from the most recent waiting list report of the NJ Division of DD (2007).

The NJ Div. of DD has pledged to increase family-driven services in the next decade. [Real Life Choices and Family Support] This change of policy reflects a change in administration at the division during this reporting period, with expected emphasis on family supports and person-centered funding.

Despite pledges for improvement there is no foreseeable end to the delay between determination of eligibility and the delivery of community-based services for people with DD under existing protocols. A realignment of the Medicaid waivers used to create community programs is projected to allow greater flexibility in funding (family-driven) and a more streamlined process. This will require at least 12-18 months to initiate. The Council continues to work with its sister agencies to mitigate and resolve these issues.

NM

Currently, there is no waiting list for those joining or transferring to the MiVia Self-Directed Waiver. The traditional DD Waiver waiting list continues to grow, as does the Disabled and Elderly Waiver waiting list because allocations have slowed. The D&E Waiver has reached current funding level capacity. The DD waiver was a little less than 4 yrs in 2002 it is now official 7 plus year and families report being told as much as 9 years.

NV

Although the number of children waiting more than 45 days for eligibility determination increased slightly, 543 new cases were added to the count in state fiscal year 2007 which was a 21% increase in caseload. Additional staff and public/private contracts helped handle the increase.

In Developmental Services, the same is true. The number waiting has remained about the same, but the total number of individuals receiving services has increased dramatically.

NY

The NYS Office of Mental Retardation and Developmental Disabilities (OMRDD) maintains two formal

waiting lists, the NYS-CARES registration list for out-of-home residential services and a listing of children who are medically complex and need services under the Care at Home (CAH) Medicaid Waiver. Following the 2005 CMS approved increase in total CAH capacity to 600, OMRDD staff worked promptly to move children from the waiting list into the waiver and effectively eliminate the CAH waiting list. Through initiatives such as OPTS and Consolidated Support Services (CSS), OMRDD has strengthened its ability to provide individualized housing services. OMRDD is currently updating its NYS CARES waiting list to identify individuals whose housing needs have already been met but indicates that less than 6000 individuals are currently waiting for out-of-home residential services. NYS CARES III was approved to provide 1,000 new out-of-home residential, 200 new day and 2,500 new at-home residential habilitation opportunities over five years. By the end of the 2007-08 fiscal year, approximately 15,000 individuals will have been served through NYS CARES. Reviews of HCBS & ICF programs have found that they exceed federal standards. ICF reviews, while complimentary, have continually noted need for improvement in: individual privacy/confidentiality; coordination & follow-up in getting needed health care & adequacy of nursing supervision; incident management w/in prescribed timelines; implementation of active treatment plans; medication & behavior management; and better management of consumer funds. OMRDD continues to actively address these areas and to reinvigorate its Medicaid Service Coordinator program.

OK

The Oklahoma waiting list has long been a source of concern to Oklahoma advocates - including the professionals who administer the waiting list. While large and growing (though still substantially reduced from a recent high of 4258 in FY 2006), the list continues to experience significant movement. For an example, for the month of October, 2007, 63 persons were removed from the waiting list while another 93 were added.

The Developmental Disabilities Services Division and the Oklahoma Department of Human Services use all available funding to meet the expanding waiting list. A major effort of the past several years has been the extensive review of "Plans of Care," as DDS noticed the trend for these plans (for persons already being served) to grow more expensive without a major change in definable costs, such as direct support pay rates. While this has caused some concern among persons being served, the resulting savings have helped reduce the waiting list AND convince policymakers (including legislators appropriating funding) that the Plans of Care were as lean as they could be.

OR

The Support Services wait list data reported above is based on the original number of people identified in the Staley lawsuit settlement agreement who were estimated to be waiting for adult services, minus those who have been served since brokerage support services began in 2001, and adjusted with data from county case management rolls. A recent poll of Community DD Programs showed a large increase in people who are or will be eligible for services by the end of the settlement agreement. Meanwhile, 815 people on the wait list received support services in FY07. The waitlist data gathered does not currently include any projections of the type of services needed.

Comprehensive Services: Access to comprehensive services happens in two ways: through the 300 non-crisis comprehensive services slots available as a result of the Staley Settlement or through crisis services. 139 individuals were reported to have entered non-crisis comprehensive services in 2007. Each county maintains a semi-formal list of individuals needing comprehensive services and uses the list when non-crisis openings arise. Oregon has no formal, statewide crisis wait list, although at any given time, dozens may be needing assistance. Each Regional Crisis Committee is given a budget to meet the needs of individuals in crisis. Many of these individuals may ultimately receive comprehensive level services. At any time, there are at least 3 children waiting for every vacant slot in the children's residential services. The State will use the Supports Intensity Scale to capture wait list information for comprehensive services once the Restructuring Budgets, Assessments and Rates project is completed.

Family Support Services:

Oregon has 3 services that support families of children with DD living at home: a Medicaid waiver for medically fragile children, a waiver for children with behavior issues; and a state general fund Family Support Program. The Medical waiver programs do not have wait lists. Eligibility criteria are extremely narrow and many families with very significant support needs cannot get access to these waivers. Each county is required to maintain a list of families waiting for the county-based Family Support Services, but data are unreliable because each county defines both the service and the waitlist differently. Undoubtedly, there are children in case management who would be eligible for family

support but are not receiving it.

PA

There are now 4407 people in Emergency status, 9436 in critical status, and 7375 in Planning status. The situation has been helped by the Governor's budget initiative, hindered by the CMS requirement to provide additional services to those already in service. The Council is a member of a legislative task force created to devise long term solutions to this problem. There continue to be no other official waiting lists in PA.

RI

The Public Housing Waiting Lists do not contain a breakdown of individuals with developmental disabilities. Also, many towns combine Public Housing and Section 8 Waiting Lists. The total individuals/families on Public Housing/Section 8 Waiting Lists is 13,850, (3882 Section 8, 5526 Public Housing, and 4442 on combined lists). Among the local housing authorities, about 41% track the number of individuals with disabilities, and that is approximately 26%. Using prevalence rate for developmental disability, we might roughly estimate that 1.8% of the applicants, or about 250, probably have a intellectual and developmental disability with the range extending upward to include individuals with other disabilities to 3600 people.

While the RI Dept. of MHRH, Division of Developmental Disabilities reports that it does not have a waiting list for eligibility determination, the Council's experience in speaking with individuals and families who call for referrals and advocacy, as well as with provider representatives, is that some families determined eligible for DD services are contacting agencies and being informed that the agencies have insufficient funds and/ or insufficient workers to provide services to all who require them. For the foreseeable future, the Office of Rehabilitation anticipates serving customers who meet the first two categories only of its Order of Selection (Approx. 70% of individuals in each year are anticipated to be from Category 1, with the remainder from Category 2). The RI Dept. of Human Services has received a Robert Wood Johnson foundation Cash and Counseling grant called "Personal Choice". The program began taking new people as of January 1, 2006. This has alleviated the aged and disabled waiting list and added elderly applicants who wish to stay at home as an alternative to nursing home placement.

DMRS was taking people off the waiting list and putting them into Waiver services, but their budget ballooned and they have stopped. DMRS Waiting List is for Waiver HCBS (residential, day, and employment). Family Support is an incredibly flexible program, but is funded only with state dollars, so the waiting list grows. Family Support is for whatever the family needs the money for (respite, dental, home repairs). Options program serves aging and people with disabilities and is operated by the TN Commission on Aging and Disability. DRS is under an order of selection, but they have begun to serve some people who are priority category 2, so the number has decreased. This number is for all people with disabilities. The people are waiting for vocational rehabilitation services.

UT

DSPD has a current total waiting list of 1,835 (this includes people waiting for services on the 3 waivers listed). 1,684 is the number of individuals waiting who have intellectual and/or developmental disabilities. Usually the waiting list grows by about the same number that enter services each year so we have not had too much progress in getting the numbers of people waiting reduced.

The Governor's budget has targeted funding 1/4th of the Waiting List, and the Legislature appropriated in FY 2007 \$2,021,100 toward the Waiting List and \$599,800 for funds for mandatory additional services. The unduplicated head count of individuals being served is 4,674. This is an increase of 228 people since last year.

This report reflects the first year of the Supported Employment Pilot that targets the bottom half of the waiting list. 105 people were served and there were 5 successful closures. The SE Pilot was successful in reducing the number of people on the immediate needs waiting list for supported employment services. In many cases, non-participants asked to be removed from the SE waiting list because, when offered the services, they indicated that they no longer needed the service.

The Council supported a second year of a community coalition, the Disability Community Alliance (DCA), during the 2007 Legislative Session. The DCA was staffed with a coordinator whose salary was paid for by the Council and Council staff and members were very involved with this project. We attribute the increased attention and effort by the DCA in continuing to get the Legislature educated about the needs of people waiting and the need for additional appropriations to support the waiting list.

The Health Department has recommended transition funding in their budget for Legislative approval in

order to enable 16 people to move from the ICF/MR's to community waiver services. The actual number of individuals who get the opportunity to move into the community can vary based upon the fact that the money may not stretch to support all 16 slots if the individual cases are more expensive than average. This year 12 people moved from the institutions into the community. 6 people were moved from the Utah State Developmental Center into the community. But the census continues to remain about the same there year after year because people are admitted as beds open up.

VA

Data for the MR Waiver Waiting List, a total of the "Urgent" and "Non-Urgent" lists, is as of Sept. 10, 2007 (point-in-time). The DD Waiver List is an estimate, actual #s unavailable. Although legislative action has occurred to reduce Medicaid Waiver Wait lists specifically, additional funding for various Waivers, increases in some reimbursement rates, and a Northern Virginia rate differential increase - incremental allocations are not keeping up with growing needs. The DMHMRSAS now estimates that the MR Waiver list has grown by one person per day since FY 2004. Reimbursement rates remain low, a disincentive to expansion of community services. Demand for some services exceeds staff availability. Other factors impacting the growth of wait lists include the increase in Virginia's general population, greater public awareness of Medicaid Waivers, and increase in the number of children with disabilities. To effect system change, the Board significantly increased activities to influence state policies impacting persons with DD by making public comment on several significant regulations (DMAS & DMHMRSAS). The Board continues to advocate for person-centered supports, including appropriate Medicaid reimbursement rates for support services as well as coverage for preventative dental services for adults.

The number for the DRS Vocational Services Wait List is as of 9/28/07. Since July 1, 2004, the Department of Rehabilitation Services (DRS) has prioritized cases under the Order of Selection due to insufficient funding. In October of 2005, DRS opened Category III (persons with significant disabilities with one serious functional limitation) to services, and contacted those in this category on the waiting list. As a result, DRS production significantly increased, & case service expenditures rose, impacting the case services budget. In April of 2007, DRS closed all but Category I, individuals with most significant disabilities. In FFY 2008, funding will not be sufficient to serve all eligible individuals. The DRS Vocational Rehabilitation program served 24, 504 persons in state FY 2007. The current DRS State Plan estimates that the number of persons to be served in state FY 2008 will be 22,610.

VT

VT's system is based on its Developmental Disabilities Act of 1996, limited to those with a label of mental retardation (based on an IQ below 70) or pervasive developmental disorder, with an adaptive skills component. Services can include service coordination & community, employment, clinical/crises, family, home & transportation supports. It is driven by a System of Care Plan [SOCP] which sets "funding priorities" for 3-year periods; key priorities for FY08-10 to enter the system remained unchanged: homeless; danger to safety; & about to be institutionalized; death or loss of a caregiver; leaving child protective services, with limited funds for high school graduates with jobs & supports for parents with disabilities. Current priorities continue the increased age for transition employment supports. Closure of the caseload to new children continues to divert demand to other sources, such as Medicaid's EPSDT personal care program (which offers no case management), & Children with Special Health Needs' limited respite funding. LISTS: Regional designated provider agencies are the gateway to services & maintain 2 waiting lists to track the number of people eligible who do not receive developmental services. (This tends to discourage potential applications & undercount those not assisted to go further than an initial screening call.) APPLICANT LIST: Includes all people eligible for services based on their disability but do not meet the restricted Funding Priorities in the SOCP (outlined above) The list includes both new consumers and some existing consumers with minimal services. 233 people were on the applicant list in FY07 compared with 169 in FY04 and 106 in FY03. The total cost of addressing the Applicant List would exceed \$5.2 million. WAITING LIST: The waiting list includes all people (new consumers as well as existing consumers) who meet the restricted State System of Care Plan Funding Priorities, but for whom there are insufficient funds, either through legislatively-appropriated caseload funding or reallocation of existing resources. In the SOCP VT calculated costs to fund based solely on Flexible Family Funding @ \$1122 per family + admin (37,912) As of 12-21-06 there were 31 on this list compared with 9 in FY06 & 44 in FY 04. Given that SOCP priorities remained unchanged the 50% jump in the applicant list underscores the inadequacy of funding to meet needs even using a narrow definition.

WA

The State's Division of Developmental Disabilities (DDD) reports that about 36,000 people are enrolled in intellectual and developmental disability (dd) services. Of these, 20,000 receive services in the community and 943 are

residents of one of the 5 RHCs operated by the state. The rest, 14,000, may not have any other support than case management from the State's DD system. DDD maintains a list of 5,000 people who are waiting for state funded Family Supports.

For Waivers, DDD maintains that they do not operate a Waiting List. Instead, they enroll recipients in Waivers using an order of selection based upon legislative priority, emergent need (crisis) and qualification for Medicaid. On July 1, 2006, there were 9,748 people on one of the 4 Waivers. By June 30, 2007, the 4 Waivers had only 9,585 recipients. Apparently, people transferred among the Waivers, died, or moved to another state.

Although DDD is unclear about the use of a Waiting List, they acknowledge that about 11,000 people who have been determined eligible do not consistently receive paid supports. Given the estimated number of people with developmental disabilities in Washington State, 112,000, it is obvious that a huge pent up demand exists for people who may on any given day need dd services.

WI

Waiting lists overall continue to grow longer and longer (except for the Family Care counties and the Vocational Rehabilitation program). Some people have been able to come off of waiting lists in some counties and receive community services, while many others have had to move onto waiting lists. Some counties have smaller waiting lists, while the waiting lists in other counties have grown. Family Care will be expanded statewide over 5 years and significant funding was included in the 2007-9 approved state budget to enable those counties converting to Family Care in the next 2 years to eliminate waiting lists for long-term care. Funds were also included in the 2007-9 state budget to address the waiting lists for Family Support and Children's Waiver slots.

WV

The Medicaid A/D Waiver has no persons on a wait list.

WY

The waiting list for the Adult, Children's, and Acquired Brain Injury waivers was eliminated in March 2005. Starting in July 2006 the Developmental Disabilities Division had to begin a waiting list for waiver services. Throughout the year a number of children and adults have been funded. These numbers are not necessarily the same people waiting for services. The ABI waiver received appropriations to fund and their should not be a waiting list through the end of the biennium. Families have been seeking services for their children at a rapid pace. The average age of the child is 10.5 years.

Source: Data reported in the Annual Program Performance Report of State Councils on Developmental Disabilities and compiled by the Administration on Developmental Disabilities, ACF, HHS, 2007.

APPENDIX E. RESOURCE LINKS

American Association of Intellectual and Developmental Disabilities: <http://www.aamr.org/>

Centers for Medicaid and Medicare Services Home and Community-Based Waiver Services:
<http://www.cms.hhs.gov/home/medicaid.asp>

Closing the Gap in Texas: Improving Services for People with Intellectual and Developmental Disabilities.
Human Services Research Institute. (October 2008). www.hsri.org

Nebraska Department of Health and Human Services Division of Developmental Disabilities:
<http://www.hhs.state.ne.us/dip/ded/dedindex.htm>

Nebraska Planning Council on Developmental Disabilities: <http://www.hhs.state.ne.us/ddplanning/>

LR 283 BSDC Direct Care Employee Survey Results

(92 surveys returned)

1) I have received the training I need to do my job effectively.

3% Strongly Disagree **5%** Disagree **20%** Neutral **48%** Agree **24%** Strongly Agree

2) I am recognized and appreciated for doing good work.

10% Strongly Disagree **40%** Disagree **23%** Neutral **23%** Agree **4%** Strongly Agree

3) There are enough staff in my unit to meet the needs of the people we serve.

14% Strongly Disagree **35%** Disagree **21%** Neutral **25%** Agree **5%** Strongly Agree

4) My supervisor has clearly communicated my performance goals to me.

11% Strongly Disagree **22%** Disagree **17%** Neutral **36%** Agree **14%** Strongly Agree

5) Abuse and neglect policies have been clearly explained to me.

0% Strongly Disagree **7%** Disagree **7%** Neutral **52%** Agree **35%** Strongly Agree

6) In my unit, we provide our clients with quality service.

1% Strongly Disagree **6%** Disagree **10%** Neutral **37%** Agree **47%** Strongly Agree

7) I have confidence in the decisions made by the leadership at BSDC.

46% Strongly Disagree **30%** Disagree **18%** Neutral **4%** Agree **2%** Strongly Agree

8) My job provides me with a sense of personal accomplishment.

2% Strongly Disagree **11%** Disagree **12%** Neutral **48%** Agree **27%** Strongly Agree

9) I feel that BSDC views me as an essential part of their long-term success.

24% Strongly Disagree **34%** Disagree **23%** Neutral **16%** Agree **2%** Strongly Agree

10) During my employment at BSDC I have been treated fairly.

22% Strongly Disagree **30%** Disagree **22%** Neutral **23%** Agree **3%** Strongly Agree

11) Employees are generally informed on a timely basis about major developments and decisions that affect them.

40% Strongly Disagree **37%** Disagree **12%** Neutral **11%** Agree **0%** Strongly Agree

12) My roles and responsibilities have been clearly communicated to me.

1% Strongly Disagree **24%** Disagree **23%** Neutral **45%** Agree **7%** Strongly Agree

- 13) In general, workforce policies are administered fairly and consistently at BSDC.
37% Strongly Disagree **33%** Disagree **13%** Neutral **16%** Agree **1%** Strongly Agree
- 14) When employees raise issues of workload and stress, their voices are heard.
42% Strongly Disagree **39%** Disagree **14%** Neutral **3%** Agree **1%** Strongly Agree
- 15) Input from outside consultants have positively impacted the work environment at BSDC.
41% Strongly Disagree **31%** Disagree **20%** Neutral **7%** Agree **2%** Strongly Agree
- 16) Direct care staff are familiar with residents and their needs.
0% Strongly Disagree **2%** Disagree **15%** Neutral **48%** Agree **34%** Strongly Agree
- 17) Staff training has improved during the past year at BSDC.
2% Strongly Disagree **14%** Disagree **40%** Neutral **40%** Agree **4%** Strongly Agree
- 18) Interdisciplinary teams meet on a regular basis to identify, discuss, and address individual and systemic issues.
5% Strongly Disagree **16%** Disagree **31%** Neutral **38%** Agree **9%** Strongly Agree
- 19) The conclusions and action steps of interdisciplinary teams are conveyed across shifts in order to ensure continuity and consistency with regard to implementation efforts.
13% Strongly Disagree **29%** Disagree **26%** Neutral **27%** Agree **4%** Strongly Agree
- 20) BSDC has placed an emphasis on identifying and analyzing resident-to-resident interactions that create risk of harm and/or actual harm.
4% Strongly Disagree **9%** Disagree **36%** Neutral **44%** Agree **7%** Strongly Agree
- 21) If suspended, I would rather be placed in a temporary position without direct contact with residents rather than stay away from BSDC until the investigation is completed.
3% Strongly Disagree **18%** Disagree **25%** Neutral **24%** Agree **30%** Strongly Agree
- 22) Transition of residents to community-based programs is being done in an effective and safe manner.
34% Strongly Disagree **29%** Disagree **25%** Neutral **11%** Agree **1%** Strongly Agree
- 23) Each resident is provided with a minimum of five hours per day of off-residence skills training that meet their needs.
10% Strongly Disagree **25%** Disagree **34%** Neutral **29%** Agree **2%** Strongly Agree
- 24) Psychologists have developed and implemented positive behavioral support plans for residents with behaviors.
3% Strongly Disagree **29%** Disagree **36%** Neutral **29%** Agree **2%** Strongly Agree

25) BSDC has developed and implemented effective measures to minimize significantly or eliminate entirely the use of mechanical, physical, and chemical restraints on BSDC residents.

0% Strongly Disagree **13%** Disagree **48%** Neutral **34%** Agree **4%** Strongly Agree

26) Staff are adequately trained on the proper use of restraints.

1% Strongly Disagree **13%** Disagree **26%** Neutral **43%** Agree **16%** Strongly Agree

27) There are a sufficient number of adequately trained health care staff, including physicians and nurses, on each shift to provide adequate protections, supports and services to residents at all times.

12% Strongly Disagree **43%** Disagree **16%** Neutral **25%** Agree **3%** Strongly Agree

28) During the past year, my supervisor provided a thorough and thoughtful performance review.

21% Strongly Disagree **22%** Disagree **16%** Neutral **29%** Agree **12%** Strongly Agree

29) I would like to complete additional higher education classes/degrees that would qualify me for a job promotion.

2% Strongly Disagree **13%** Disagree **36%** Neutral **27%** Agree **22%** Strongly Agree

30) I have worked at the Beatrice State Developmental Center for:

9% less than 1 year **15%** 1 - 3 years **12%** 3 - 5 years **23%** 5 - 10 years **41%** 10+ years

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Developmental Disabilities Special Investigative Committee
April 15, 2008

[LR283]

The Developmental Disabilities Special Investigative Committee met at 12:00 noon on Tuesday, April 15, 2008, in Room 2102 of the State Capitol, Lincoln, Nebraska.

Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Abbie Cornett; Tim Gay; Arnie Stuthman, and Norm Wallman. Also present: Senator L. Pat Engel, Chairperson, Executive Board. []

SENATOR ENGEL: (Recorder malfunction)...and get this over with. Basically, the only reason I'm here is to call the meeting to order and go through the first round of elections, as far as who is going to be your Chair. Once the Chair is elected, then I'll turn it over to the Chair, and then you go to the Vice Chair after that. So I'd open for the floor for nominations and we're going to vote by ballot, by secret ballot here, is how we're going to do it, so...and if there are no nominations on the floor, we'll just pass it out and you can start voting, so however you want to do it. [LR283]

SENATOR CORNETT: I know that I've talked to Steve. I'll nominate Steve. I'll nominate Steve. [LR283]

SENATOR ENGEL: As Chair? [LR283]

SENATOR CORNETT: Yes. [LR283]

SENATOR ENGEL: Okay. [LR283]

SENATOR GAY: I'll second. [LR283]

SENATOR ENGEL: And seconded by Senator Gay. Is there any discussion on...? Would the nominee himself like to speak, or would you just like to vote? [LR283]

SENATOR STUTHMAN: I think we should vote. [LR283]

SENATOR LATHROP: I think we can probably just vote. [LR283]

SENATOR ENGEL: Okay. [LR283]

SENATOR LATHROP: I appreciate the nomination and the second. [LR283]

SENATOR ENGEL: Okay. Okay, then pass out the...well, I guess we can just call the roll on this, if that's the case. Are there any other nominations? [LR283]

SENATOR STUTHMAN: Mr. Chair, I move the nominations cease and Senator Steve Lathrop be elected by acclamation. [LR283]

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SENATOR ENGEL: Okay. Okay. All those in favor say aye. You now are Chair, sir. You now can come up here and you can take over, sir, and I'm going to go see the Pope. [LR283]

SENATOR LATHROP: All right. Tell him I said hello. [LR283]

SENATOR ENGEL: I will. Congratulations. [LR283]

SENATOR LATHROP: Thank you, Pat. I appreciate that. [LR283]

SENATOR ENGEL: Anyhow, you guys got a real responsible job and it's going to take a lot of time, and I know we got the right people on the committee to do it. So I'm real anxious to find out what the results are, so... [LR283]

SENATOR ADAMS: Say hi to the Pope. [LR283]

SENATOR ENGEL: Bye (inaudible). [LR283]

SENATOR STUTHMAN: Thank you. [LR283]

SENATOR ENGEL: (Inaudible.) [LR283]

SENATOR GAY: Did a fine job. [LR283]

SENATOR LATHROP: Yeah. Well done. Well done. If we're ready, I think our second order of business is to elect a Vice Chairperson and for that, I guess we'll look to the commission for nominations for Vice Chair. [LR283]

SENATOR GAY: I'd nominate Senator Harms. [LR283]

SENATOR WALLMAN: I'd second it. [LR283]

SENATOR LATHROP: All right. There's a second. Any additional nominations? [LR283]

SENATOR STUTHMAN: I move the nominations cease and a unanimous ballot be cast for Senator Harms. [LR283]

SENATOR LATHROP: All in favor say aye. Any opposed? All right, we have ourselves a Vice Chair. The third item on the agenda is miscellaneous, and I suppose that would bring us to a discussion of timing as much as anything. Maybe the first order of business is just to figure out what people are thinking, in terms of the time they have, when are good times to meet and how we're going to coordinate the meetings and the

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taking of testimony. [LR283]

SENATOR HARMS: Can I ask you a question? When we put the time together, are we just going to do a block of time and just continually... [LR283]

SENATOR LATHROP: I think, given that you are coming from Scottsbluff, we don't want to do it every Monday. [LR283]

SENATOR HARMS: Yeah, it would be so much easier for me. But I'd like to just have a block of time that we just complete this project, where we just concentrate it, because I've been on similar situations like this and what I found is by breaking this thing out and coming, you know, every other week, you start to lose the perspective of everything. That's why it's important to get engulfed in the whole issue and try to find solutions to it, rather than spread it out over a long period of time. I don't know how the rest of you feel, but I've done that with institution of higher education, gone in and helped with troubled colleges. It's just difficult if you don't stay with it. [LR283]

SENATOR LATHROP: And when you say stay with it, are you talking about... [LR283]

SENATOR HARMS: I'm talking about a week at a time or whatever it takes. [LR283]

SENATOR LATHROP: ...trying to do...trying to take a block or a week and... [LR283]

SENATOR HARMS: Or two weeks, whatever it takes. [LR283]

SENATOR LATHROP: Now that we have people going back to their other lives, maybe we ought to have some input on whether that...I'm agreeable to that myself, but we ought to figure out how it works for people that are trying to bank and...anyway, Arnie. [LR283]

SENATOR STUTHMAN: Senator Lathrop, I, you know, I agree with the fact of taking a time frame, but I think we, as you as Chairman, ought to figure out, you know, what the plan is; you know, what are we going to look at; what issues are we going to discuss; what people do when they get involved in it. And I think we need to get that first before we decide, you know, we're going to take a week and we don't have no real direction as to what we're going to do that week. [LR283]

SENATOR LATHROP: Do you want to take the time today to do that, or do you want to give some thought to what your ideas are on where we want to go and then reconvene before, say, on Thursday; just take some time over the lunch hour to sit down and say these are my ideas on what we ought to look at, so that we have kind of an outline of what we want to do? Is that what you're thinking? [LR283]

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SENATOR STUTHMAN: That's kind of what I have in mind. I feel, you know, that you, as the Chairperson, maybe ought to try to get some of those, you know, key components itemized as to what we need to look at and where we can be effective and stuff like that. [LR283]

SENATOR LATHROP: I'd be happy to do that. I'd be happy to do that and provide an outline of maybe the areas of inquiry, and the things that we want to look at and the direction we want to go or the directions we want to go in, and then I can share that with you. It might be a good idea to try to meet one more time, like on Thursday, before we...every scatters. [LR283]

SENATOR STUTHMAN: I think that would be good. And then, you know, as to, you know, do we visit the facilities, would we take one day, whether we take a day to visit and then discuss some of the items on your agenda and then come to some type of a conclusion. [LR283]

SENATOR CORNETT: The other thing that I think is very important is we have a lot of documents in my office. I have three large notebook folders of information that I've gathered over the past year in regards to the reports for the last four years from Beatrice from the federal government, what Health and Human Services has provided us, the difference between the first report that they provided us and the second report, the miscommunication or inaccurate numbers. But I think that before we make any definitive plans and start, you know, telling people we need to, you know, we're doing hearings and meeting over this time period, that I think that everyone on the committee should have time to go through that information and consolidate questions or concerns. So I mean besides you doing what the concerns are, I think that we should try and get copies of that information to everybody on the committee so they have a chance to look it over. [LR283]

SENATOR LATHROP: Are they...you said four boxes? [LR283]

SENATOR CORNETT: No, binders. [LR283]

SENATOR LATHROP: Binders. Oh, okay. I thought... [LR283]

SENATOR CORNETT: And they are organized and I will get copies of all the data that I have on Beatrice and everything that has been provided to me from Health and Human Services and distributed to the committee. But I'll be frank, I cannot do that before Thursday. [LR283]

SENATOR LATHROP: Okay. I do think that probably the first meeting we ought to arrange for a visit down to Beatrice and a visit to, if there's such a thing, a typical community-based provider, so that we have some frame of reference for the types of

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care that are provided and what we're talking about when we talk about either one of them. [LR283]

SENATOR CORNETT: The other thing that we need to look at, because one of the issues is removing people from Beatrice and putting them in community based, is, since you're the Chair, having the staff find out exactly what is available throughout the state in community-based services, what the waiting list is and...because I know that we keep talking about moving everyone to community-based services but there are no community-based services in a lot of areas. Where are these people going to go? And where there are community-based services, there's huge waiting lists. So everybody keeps saying move everybody to community-based services, but we need to know what's available in that regard. [LR283]

SENATOR LATHROP: It makes perfect sense, I thank you, that that certainly has to be part of our inquiry as we go forward and try to say how do we solve or how do we provide for the care of the developmentally disabled and as between community-based care and Beatrice, and what are the challenges in moving more people to community-based care if that's what's the right thing to do in the first place. Perhaps we should get the binders from you. It sounds to me or it makes sense to me that we'll probably need to meet one time just to kind of set sort of our agenda, make sure that we agree on or that you're okay with whoever committee counsel is or whatever staff we have, and the direction we go in. That ought to be something we do as a committee so that we're all on the same page and we can have an outline of what we're going to do, the direction we're going to go. And then we can figure out when we can all meet, how to accommodate everyone's schedule so that if the Gays are on vacation we're not sitting important witnesses on the same day. And then we'll have an outline so that we know what each witness...or have an idea what each testifier is going to say when they come before us. [LR283]

SENATOR CORNETT: If it would be all right with you, Steve--since this is the last week of session, I was going to kind of let my staff take it easy on Friday--start getting those binders copied and together and packets for everyone next week, beginning of the week. [LR283]

SENATOR LATHROP: Okay. Well, I think John has the longest drive in. Are you... [LR283]

SENATOR CORNETT: We can mail. We can ship it to you. I won't... [LR283]

SENATOR LATHROP: Okay, let's do that and then figure on about, what are we going to need, two weeks to go through the binder? I'll develop an outline and then we can come back and talk about sort of our process, the direction we want to go in, how we're going to get there and who we're going to use to help us get there. [LR283]

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SENATOR CORNETT: And, Arnie, would you want yours shipped to you also? [LR283]

SENATOR STUTHMAN: Yeah, please. [LR283]

SENATOR ADAMS: You can just have it...to my office. [LR283]

SENATOR CORNETT: To your office? [LR283]

SENATOR ADAMS: Yeah. I'm in all the time anyway, so... [LR283]

SENATOR CORNETT: Tim, you want it (inaudible)? [LR283]

SENATOR GAY: Just office is fine. [LR283]

SENATOR STUTHMAN: Abbie, you can either take it to my office and then we'll make a decision. I might be coming down, you know, within a day or so. [LR283]

SENATOR CORNETT: Or your staff can mail it to you, if you're not. [LR283]

SENATOR STUTHMAN: Yeah. Yeah. [LR283]

SENATOR CORNETT: All right. [LR283]

SENATOR STUTHMAN: That would be good. [LR283]

SENATOR CORNETT: Well, we'll just assume that yours is going to get mailed. Okay. [LR283]

SENATOR LATHROP: Tim. [LR283]

SENATOR GAY: I'd just say we do have the resolution actually that was written, that we follow it; otherwise we could go completely off base here. But on some of that, on page 4, it said we shall utilize any existing studies and reports, and I'm sure there are a lot that have been done in the past that maybe we should look at and get some copies of those, too. Or if anyone finds anything along the way that they feel is pertinent to include, we have some center. Maybe we forward it to you or whoever staff is to then distribute accordingly. Because there's probably mountains of information out there already. Senator Cornett has some more to add, but if we have anything to add or if others in the public want to add something to it, that they have one central place to go, yourself, and then you can distribute out accordingly. [LR283]

SENATOR LATHROP: That's fine. That's fine. Are you...do you know if Health and

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Human Services, your committee... [LR283]

SENATOR GAY: I'm sure they would probably have some things, don't you think, Senator Stuthman? I'm sure they will, which they should. [LR283]

SENATOR LATHROP: If you can talk to Jeff or whomever would have that cataloged and find out whatever studies so that we don't have to reinvent the wheel. [LR283]

SENATOR GAY: Yeah. And then on the fact of I trust you. Senator Harms would be, you know, from complete different ends of the state, whatever you guys want to do. I do agree with Senator Harms that at some point, if it's the third week of each month, we kind of know and you pick four or five dates and here's what we're going to cover. And there will be some times where, you know, maybe Senator Adams can't make it, whatever. Or if we want to go, you know, further out, if we're looking at community-based services, that means statewide, so if we want to do these things and get public opinion anywhere else, I wouldn't mind going and doing that as well if we have something to go, but I would assume everyone would, but whatever you guys work out because you are from complete different ends of the state. And I think that would be agreeable probably to everyone. [LR283]

SENATOR LATHROP: Okay. I guess we're blessed with people that are retired so that makes it a little easier than having...well, I'm certainly not. [LR283]

SENATOR CORNETT: I was going to say it will be...if we start the blocks of meetings, it will be easier for me when my day-care person is out of school,... [LR283]

SENATOR LATHROP: Okay. [LR283]

SENATOR CORNETT: ...and she'll be done the first week of June or last week of May. [LR283]

SENATOR LATHROP: Okay. I think... [LR283]

SENATOR CORNETT: But I can do the one-day meetings. That's not a problem. But if we were talking like ten-day blocks or something like that, it would be easier if I had... [LR283]

SENATOR GAY: (Inaudible) me too. [LR283]

SENATOR CORNETT: Yeah. (Laugh) It would be easier if I had day care arranged. [LR283]

SENATOR LATHROP: Okay. I just think as a matter of a beginning point, maybe we'll

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pick something up two weeks out, meet and perhaps run down to Beatrice and take a tour and if we can find a community-based care provider that would be a typical situation when you start out with a tour, so we have a frame of reference, and then we can sit down and talk about the dates that we meet and the subject matters and then any other studies or work that's already been done that we can consider so that we don't have to reinvent the wheel. John. [LR283]

SENATOR HARMS: One of the things I'd like to have us do as we start to prepare this and just before we go in, I'd like to have us bring in the Fiscal staff or I don't know if it's Liz or Jeanne, whoever deals with that aspect of Beatrice. We need to have them come in and talk to us a little bit about the fiscal issues they see there, as well as any other issues they might know, because they know a lot, and I didn't realize that until I got on Appropriations Committee, because they lived with this. They might be able to help us also, so I we have some idea...because it's all going to roll down to, as we put this package together, how are we going to finance everything. I think there's money there that's not being spent. We just need to get a handle on that before we go in so that we know what we're talking about and have a better picture of this. [LR283]

SENATOR LATHROP: Okay. If you can find out who that is. [LR283]

SENATOR HARMS: I know. (Inaudible). [LR283]

SENATOR LATHROP: Maybe if you can, rather than have them at the front side, maybe you can talk to them so that you can bring us some background and then eventually, in the process,... [LR283]

SENATOR HARMS: Sure. [LR283]

SENATOR LATHROP: ...we'll have them come in and testify so that we have it in the record and it's... [LR283]

SENATOR HARMS: (Inaudible.) [LR283]

SENATOR LATHROP: ...it's not secondhand. [LR283]

SENATOR GAY: Are we looking at a snapshot, maybe when we do this tour, whatever, just a snapshot of where we are now,... [LR283]

SENATOR LATHROP: I think that's all we can do. [LR283]

SENATOR GAY: ...where we want to go, and that's what you're doing? [LR283]

SENATOR LATHROP: If we do a tour...if we do a tour, all it will tell us is what things are

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like on the day we went there and... [LR283]

SENATOR GAY: Sure, and where...our starting point. [LR283]

SENATOR LATHROP: Right. It will...but it will give us some background that I think will be useful when we're talking about the level of disability by the typical resident and the facilities that are available. [LR283]

SENATOR WALLMAN: There is a huge difference in the range of disabilities there. [LR283]

SENATOR LATHROP: I suspect so, and I don't have expertise in developmental disabilities so we'll need that. Senator Stuthman. Oh. [LR283]

SENATOR WALLMAN: And a private care provider in Beatrice I think is full. Mosaic is full, I think. Isn't it, Tim? [LR283]

SENATOR GAY: Yeah. [LR283]

SENATOR CORNETT: Mosaic is full pretty much everywhere (inaudible). [LR283]

SENATOR STUTHMAN: I think it's very good...very good to take the tour and set up kind of your basic ground of the plan of what we intend to do. [LR283]

SENATOR LATHROP: Yeah. [LR283]

SENATOR STUTHMAN: I think that's very important on the first shot. And I think most important is the tour, to start with, so that we can get a snapshot of it. [LR283]

SENATOR LATHROP: Okay. Good. then it sounds like we're all on the same page. All right. We will...I'll get a hold of your offices and will just roughly plan on something about two weeks out. No? Not enough time? [LR283]

SENATOR CORNETT: No, two weeks is fine. I thought you were asking if I had any questions? No. [LR283]

SENATOR LATHROP: Oh. Oh. You made a face and I didn't know if that was a... [LR283]

SENATOR CORNETT: No, I was thinking about something else. [LR283]

SENATOR LATHROP: Okay. [LR283]

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SENATOR STUTHMAN: It's not a two-week tour. [LR283]

SENATOR LATHROP: All right. [LR283]

SENATOR CORNETT: At that point, you become a patient. (Laugh) [LR283]

SENATOR LATHROP: Anything else anybody else wants to take up while we're together? Okay. I think we're adjourned. Thanks. [LR283]

Chairperson

Committee Clerk

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[LR283]

The Developmental Disabilities Special Investigative Committee met at 9:00 a.m. on Monday, June 23, 2008, in Room 1507 of the State Capitol, Lincoln, Nebraska. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Abbie Cornett; Tim Gay; Arnie Stuthman, and Norm Wallman. Senators absent: None. [LR283]

SENATOR LATHROP: My name is Steve Lathrop. I'm the Chairman of the commission that was established by the Legislature to evaluate developmental disability and the care provided to the developmentally disabled by the state of Nebraska. Today is our first hearing. And I'd like to start, if I may, by giving you a little background. Maybe I should introduce the other members of the commission, and then I want to visit with you a little bit about the structure of our hearings today and tomorrow, as well as the structure of how we're going to proceed with this inquiry over the coming months. I'm joined today by other members of the commission which include Senator Norm Wallman, who is seated to my left, Senator Adams from York, Senator Gay from Papillion, Beth Otto who is our clerk, Sean Schmeits who is my legislative assistant, and also John Harms from Scottsbluff, Senator Abbie Cornett from Bellevue, and Senator Arnie Stuthman from Columbus. We are the commission that has been appointed pursuant to LR283, which brings us here today. We have in our effort to develop some structure to how we're going to make this inquiry concluded that the best approach for us as a commission is to hold two days of hearings each month between now and the time our report is due on or before December 15. In June, today, we are going to take up what I would generally regard as background issues. We have invited speakers to discuss those matters. I am familiar with the fact that, and I have received, as we all have, an awful lot of e-mails and inquiries from people who have an interest in this matter. We're glad you're here and in attendance. We have heard from a number of family members who have people that are family members that are either at Beatrice or receiving community-based care. We will make time for testimony from those people, from those family members, and from those guardians, but it probably won't be until August. Our August hearings will include an opportunity for people to tell us what their family's experience has been with Beatrice, also to have employees at Beatrice or otherwise in the system to testify concerning Beatrice and the care that's provided there, and perhaps the staffing issues that are prevalent. Today what we will take up is, and this is to give you a little bit of an outline of what we will do and how we'll proceed today and tomorrow. We are going to initially take up background just to educate the members of the commission on the background of people with developmental disabilities, the spectrum of their disabilities, as well as their needs. And Dr. Bruce Buehler is here to testify about that. He was formerly the director of Munroe-Meyer Institute in Omaha. We will also take up and listen to testimony from invited speakers on the subject of the legal requirements the state has to families and folks with developmental disabilities. And we will have and hear from Bruce Mason, with NAS, and also from Ms. Fenner, and I think

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she's with Health and Human Services. She's a...after we hear or take testimony regarding the legal requirements, we will also then take testimony regarding resources. And we will hear from John Wyvill, who will give us an overview of Health and Human Services and the way Health and Human Services provides resources to families with a loved one that has developmental disabilities. John will also provide us with other testifiers who will take more specifically, including Ron Stegemann, from Beatrice Development Center, to talk about what services are provided at Beatrice, what services are provided in the community. And then last...the last thing we'll take up today will be the number of people receiving services so that we get an idea of the census or the population of people receiving services from the state for developmental disabilities. And that discussion will also include an overview of the waiting list--what it takes to get on the list, what does the list look like, how many people are waiting, and what kind of services are they waiting for. So that's an overview of what we're doing. You can see, with the people invited to testify today that we probably won't have time to take testimony today from the public, although we remain very interested in what you have to say, and you're welcome to talk to any of us. We will afford folks an opportunity to testify in one of the upcoming hearings. A couple of housekeeping things. If you testify, we need to have you fill out a sheet that will provide us with your background. Those sheets are up here, Beth? [LR283]

BETH OTTO: Yes. [LR283]

SENATOR LATHROP: Okay. If you have any handouts, you can provide them to us and we'll pass them out. Hopefully, you've brought seven copies if you do have handouts. And otherwise, I guess, we'll just get started. And with that, we'll ask Dr. Buehler to testify. [LR283]

DR. BRUCE BUEHLER: First, I'll try a kind of broad base and talk about developmental disabilities and all. But, I think, the easiest way to do this is please interrupt me at any time, makes it easier. [LR283]

SENATOR LATHROP: And I'll do that first by asking you to tell us your name and tell us your business address and spell your last name for us, if you can. [LR283]

DR. BRUCE BUEHLER: I'm Bruce A. Buehler, B-u-e-h-l-e-r, M.D. And right now I'm at the University of Nebraska Medical Center. And I'm executive director of the Center for Human Genetics at the university. Maybe it would be helpful to tell you a little bit of background then? [LR283]

SENATOR LATHROP: I think that would be a good place to start. [LR283]

DR. BRUCE BUEHLER: I started out in 1974 as the director of the Sunland Training School, which is the regional center, comparable to Beatrice, in the state of Florida. I

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was the medical director there for a period of time, and then I moved to medical director of Utah State Training School at American Fork, which also is the regional center for the entire state of Utah. And from there I came to Nebraska, in 1981. And since then I've essentially worked in the community with individuals with special needs, developmental disabilities, developmental delays. And I do clinics throughout the state. I spend time on the road about two months a year in Scottsbluff, North Platte, Kearney, Grand Island, Hastings, and we also have some clinics in both Winnebago and Omaha. So we have been very involved in dealing with children and adults with special needs, which is probably the broadest term. So how would you like me to proceed, sir? [LR283]

SENATOR LATHROP: Well, I appreciate the background and that's very helpful. And now maybe you could share with us and educate us, if you could, with respect to the spectrum of people with developmental disabilities and what their needs are, sir. [LR283]

DR. BRUCE BUEHLER: Unfortunately, the term developmental disabilities is a federal term. It's a term that is mandated. And you all know the law, and you know what it says. But in reality it's any child with special needs. And that's probably a term that's grown over the years because many of the individuals may have only an orthopedic issue and be developmentally close or often even okay. The biggest change that's happened over the years is, when I started in the seventies, we essentially tended to go toward institutionalization for children under a certain level of function. Today because of the community movement, because of other issues, we have moved a large number of those children back in or kept them in the community from the beginning. And probably the overriding view today in developmental disabilities is as much as possible inclusion. And inclusion being that you can actually stay in your community, and if possible in your home, but if not possible within some type of setting. But you also will have the chance to interact with your peers, work with individuals of your same chronologic age, and learn the social skills, which is as important as the intellectual skills. Where we have come into problem, and it's a problem that we see, I think, in many areas, but in developmental disabilities, because it's such a broad base, behavioral issues fall into that category. And we have to remember that when we say somebody has a developmental disability and is able to function in the community that's excellent, and that's where they should be. But if you have a child or an adult who has a developmental disability but is unable to control themselves, is unable not to injure themselves, it not able to not injure others, then we have very few options because the community is not set up at this time to take care of severe behavioral developmental disabilities. And what are we talking about? Well, the original group that we saw in this category would be people that were untreated for certain metabolic diseases, which thank goodness we now have a state metabolic screening program, newborn screening which has weeded out a lot of these children early and allowed them to have a normal life span by diet and intervention. But many of those individuals weren't picked up in the sixties and had to go to institutions. They have self-abusive behavior, they will actually

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injure themselves severely, they will injure others, and it's not that we can easily behaviorally manage those issues. And for the community it's a very difficult task because these individuals are often aging, they're getting older, they're bigger, and for physical reasons they need one-on-one, two-on-one, three-on-one types of care. So right now in the state what we look at is trying to start with a newborn or an infant that I see in a clinic. And the first thing I'm going to do is look to see if I can find a diagnosis. And why are we diagnosing them? Because we can get school systems started immediately if we have a diagnosis. And this is either called other health impaired, or falls under the mental retardation dogma, which is essentially an IQ of 70, which you can't test in a newborn, obviously. So what we do is we get them into the systems early. This has made a major difference in the demographics. We've been able to keep many children in the community because of early diagnosis and because of early intervention. The problem is we've also stressed the system because we have diagnosed these children three, to four, or five years younger than they would have been in the past. About four or five, this child would have showed up in my office showing delays. Today I'm diagnosing them at birth. That's four or five more years that the education system has to respond. And so it has put a fairly significant burden on the community. Because we have newborn screening, one of the big advantages has been children with PKU, who were a significant number of children in institutional settings. Children with other metabolic diseases we're now screening for that. And about 95 percent of those children are not only treatable, but actually do not require special ed services later in life. So screening has become a major change in the demographics in order to try and catch the children early and prevent the disease. We've also been able to work with families where there is a history of problems, and we've been able to work with them early and get those children started earlier because of the genetic history and/or the background. So the demographics have changed because the children can be picked up earlier, therefore in community services. But what we have found is that getting children into an early program is not only important from the intervention standpoint, but what we've found is that most children who are functional can be independent, can do their dressing, do those other types of things, require one big issue, and that's socialization. So one of the areas that we are working on but still have a great need for is the schools are required for both cognitive and all the things that they do to educate, but socialization is becoming one of the major issues that we'll be facing for those individuals who stay in the community. A child with autism needs cognitive training, but a child with autism needs to understand how to walk in a room and say hello, and welcome you and know that there's something they should do. As one young person with autism told me, I have to Google what I'm thinking, because I don't know what to do, but I can bring it up on a card and I know what to do that way. So our schools have moved not only into cognitive, but heavily more into socialization. As you would guess, institutionalization is not an easy socialization issue. It's not easy to set up a socialization program of your peers and drive that. And so we are very cautious today in putting individuals into an institutional setting when they have potential to socialize and to develop certain skills. Then why would we be looking at any issue of individuals

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having to be in more of a restricted environment? Today I would say the majority of issues are not as much physical as behavioral. Once you deal with individuals who have special needs sometimes the behaviors become beyond any system we can work. And the most common behavior is self-abuse and other forms of abuse. And this is not within the purview of most communities to essentially give those services. And so if you start looking at the populations that are developing in centers, whether they be large or smaller, they often have dual diagnosis--they have a disability, and they have a developmental behavioral problem that creates significant need for staffing. And so I would see the dichotomy that occurs today in society is all children start, if possible, in the community setting. That's our intent. That's how they get to me, that's how they get to the schools, that's what caseworkers do and so on. But over time those children who separate out and are severe behavioral, along with physical disabilities, there has to be an alternative. I assume the committee will decide what that alternative is and what the best alternative is, but there probably today is not services for those individuals. Now an individual with developmental disabilities actually can be diagnosed up to the age of 22. So developmental disabilities encompasses a very large group. And if you take the national demographics, roughly 15 percent of the population falls in the developmental disability range. But that would include autism, that would include learning disabilities, that would include attention deficit hyperactivity disorder. It's broad, but it is a significant proportion of individuals. In general, majority of developmental disabilities that we deal with are lifelong. These are not things we're going to tomorrow are going to go away and we will have cured them. What we will have done is integrate them into the best possible. And I believe you'll hear throughout your testimonies and all of the discussions you'll have that the driving principle for children with special needs and disabilities is quality of life. We're shooting for quality of life. We're not looking to see that every child has to be the same or fit into a mold, but they have to have the ability to maximize their quality of life. And if that's best done in one setting or another setting, that requires the input. And I will say that probably developmental disabilities more than any other area of medicine and/or education requires a team. It's not something you can do as an individual. I, as a physician, cannot walk in and say, this is the best place for this young man or young woman. What I can say is this young person needs these services. And what are the agencies that we can deal with? Well, we have HHS, of course, and Medicaid system. We have insurance companies and they will pay for some of the interventions that we...are necessary. We have the schools, which are mandated, start at zero. We're one of the outstanding states, by the way, in serving young people who have disabilities of any kind. And we, in general, try to find most advantageous setting for them. One of the things that we have found is also we need to develop parent training. And so a lot of the work that we do also is to help the parents understand the issues they're dealing with. It's very easy to say I'm going to keep my child in the community and I'm going to have that child served in the community. But you have to remember that at the best they're going to get 8 hours of service in school, and there's 16 more hours of essentially 24-hour care. And parents have a huge amount of caring. So if we're going to maintain major community programs, we have to also maintain

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support for parents, because parents, like all of us, burn out. That shouldn't be an option that we can't deal with that, but it's something that you need to be aware of. And it's an expense that on the books doesn't look realistic initially, but you realize that if the parent decides to take care of their child at home, that child gets to be 110 pounds, because they grow up, how do you get them out of a bathtub? Now it's simple things that we don't think about, but it's how we do it. If that child is 250 pounds, is not cooperative, is not...then you may have to go to some type of institutional, or residential, or regional center because you can't physically and/or developmentally deal with that. Is here still quality of life? Of course, we still can maintain within any setting a quality which says the person or the client, whatever term you want to use, gets the best care. The educational responsibility right now in this state is essentially to take the individuals we identify, and they can be identified in multiple ways, I would say the majority, about 90 percent of kids, get into the system through physicians because the parents come and say, he's not walking, he's not talking, he's not speaking, she's not making milestones, you know. And then the schools become involved. And so early intervention is probably at this point one of the most usual methods into the system that we have today. The second step is then to develop a school program and to work within it. But for many of our individuals that we deal with that we diagnose early, we also have to take into account some are on respirators. They actually got to school on a bus with a tank of oxygen and a breathing machine in order to get their services. Now that is a maximum amount of effort, and it may be the best effort, but it's one that has to be done if we're going to serve them in the community. And in some cases it may be beyond what we are able to do. We have...many of our children have fairly significant seizures, and those need to be treated, if in the community, with medication given in the schools. There needs to be medical personnel in the schools because these children are actually medically fragile. And so what would have in the past, maybe 40 years ago, immediately gone to a larger institutional setting, may be in the community but requiring multiple resources. We also have a category that most people don't think of in developmental delays, which is other health impaired. These would be young people who have...a child I just diagnosed recently who has both of his arms missing, born that way. Developmentally he appears to be on scale. Looks like he can do a lot of the development, but he certainly can't function in a classroom in the same way another child does. So in that case we have to make adaptations, so the school has to offer PT, and occupational therapy, physical therapy, other forms of support in order to make that child able to be educated. And the rule of the schools essentially is to deal with anything that impairs the ability to be educated. So that means they're going to deal with orthopedic problems, they're going to deal with other problems. For potential today in dealing with the population, and by the way doing multiple state clinics I'm all over the state seeing individuals. There comes a certain point where none of the community services will be sufficient. Child is...when an adult or a child is becoming an adult the child has too many issues, the behavioral issues are beyond control, and so whatever decisions the committee has to make, there probably has to be an alternative to adjust the community, because the community may not be able, in this day and age and in this

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site to serve that individual in an adequate way. We don't want a young person nor an adult harming themselves because they can't get the support they need. And I mentioned socialization and I'll go back to it. We worked very hard on cognitive, we worked very hard for young people to learn, to reach their max, and I think it's...as long as the dictum that we're all working under is quality of life, then that's an individual issue for every person with special needs. You are going to hear the work developmental disabilities, that's a legal term. And it essentially means a disability that occurred within the first 22 years of life, the majority being around birth or soon after. You're going to hear about developmental delays. That's a whole nother term. That's a term where someone has capability, but will reach it at different points. They will learn throughout a lifetime, but they'll continue to need input. And right now that's the second step in this pattern is many of our individuals reach 21 and systems stop. There's no easy placement in the community for adults. There's no agency, essentially, other than vocational rehab, who is essentially mandated to try to help these young people now become adults and transition. So we're talking about group homes. We're talking about support systems, support systems for the family. So we need to be very sure as we think about this that we don't think of this child as 0 to 21, and then everything ends because it's not going to happen. That child is going to go on and live 60, 70, 75 years. So in thinking about finances and costs, etcetera, we can't just assume that at the end of 21 we've ended our support. And that has major fiscal implications which are far beyond me. The last point, I think, is that the number of children and adults who will continue to come into the system is going to grow, it's not going to get smaller. And the reason it's going to grow is that we can diagnose more things than we ever could. Today I could take a blood sample from you and I can do 2,500 of your genes. I can know a lot about you in a single blood sample. Or I can take a newborn who's not fitting the pattern and diagnose that child at birth that I wouldn't have even considered diagnosing until the teenage years. So the impact is that the numbers won't go down. And the question is, where is the best service, since the numbers will actually go up. And as we maintain children, especially premature infants, infants of printing, infants that have been exposed to alcohol, exposed to other agents, we are going to see an increasing population that we have to deal with. Senator, I hope that's a start. [LR283]

SENATOR LATHROP: That was very helpful. I do have...maybe invite you to talk about a couple of things while we have you here. And that is you've given us sort of a definition, you've given us the definition of developmental disabilities. Can you share with us the spectrum? We have some people with physical, as you say, orthopedic problems, we have people that are cognitively impaired, and we have some behavioral issues. And those are perhaps three of the defining characteristics of people with developmental disabilities. But in terms of the population that we provide services to are they...they come to us, some with physical, and some with cognitive. Can you maybe address the population,... [LR283]

DR. BRUCE BUEHLER: Sure. [LR283]

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SENATOR LATHROP: ...and give us an overview of that, if you would? [LR283]

DR. BRUCE BUEHLER: I'll use my clinics as kind of a way to think about how the division occurs. We see individuals who have had massive brain damage in utero, or have had an injury, not as common as we thought, but at birth, or has had a bleed from prematurity or something else. The brain is clearly damaged--hydrocephalus, water on the brain, other types of problems. These children are very clearly going to fall on that spectrum. And many of them will fall in what we call the severe, profound range. And just for your understanding, the schools use a very simple and straightforward rule, and that is IQ 70 or less is served no matter what else disabilities there are, now whether they're physical disabilities or whatever. And those are the children where we know from the beginning, as we tell the parents, they've had a static brain injury. And we're not going to fix that. What we are going to try to do is maximize the ability around that. And I use the analogy with my families that essentially, no matter what we do, let's set the bar the highest we can and see if the child can make it, but also understand we may not get there and then we have to be realistic. So we have that group of individuals who are going to be severe and profoundly retarded, and the word retarded, unfortunately, still remains in our vocabulary, and they are not going to be able to do life skills, function on their own, get up and get dressed, get their food and do those types of things. And therefore they will need care. Where that's best done usually a very personal with the family, with a team trying to decide. But do they learn? And I think the biggest issue we've all had to learn is they continue, as children and as adults, to gain some skills. But they're not going to gain enough skills for independent living, not going to happen. Then we have a population in the moderate range of developmental disabilities. And that's probably your majority. And as an example, and again only an example, I will use Downs Syndrome because we have been lucky and smart enough to put these individuals in the community and allow them a lifestyle. And they are functional. Many individuals with Downs Syndrome have an IQ well below 70, some at 70, but many have social IQs above 120. They can walk in a room, talk with you, do a job, have a quality of life, and even in some instances a marriage, whether or not they have a family. So that group is a whole different relationship. And those are the children who generally stay in the school system for the 21 years. And then we try to transition them into a setting outside. The law now is federally, I believe, it's 14. We are using 16 as essentially the milestone. At 16 we expect the children to have a transition plan. Are they going to vocational school? Are they going to go out and have a job? Are they going to learn a job while they're also learning cognitive things? And that's really important that we have that transition because otherwise then they would be dependent, and there's no need for that. We had individuals on the mild spectrum, and that's a group that's growing the largest. We've had a 400 percent increase in the number of children with autism in the state of Nebraska in the last three years. Now you can say, is this an absolute epidemic? Well, when you do data from other countries that have not had mercury in their vaccines, who have not had changes in their definitions and all, the absolute

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number of increase national or worldwide seems to be at 16 percent. But we are seeing a 400 percent increase, and that means we are diagnosing it and had missed it, or we're opening our criteria. So the second level or the third level is those individuals who, with education, with socialization, should be very functional. And that is the mild range. And that's the area where we've had the greatest success, and that's where the community does best is taking those children (inaudible). Now what about the orthopedically handicapped? Well, we get a lot of children who have cerebral palsy. And it's a very broad useless term in many ways. But many of them are physically involved enough to be wheelchair bound, to need intervention, to need care in the schools and all that. And they require a huge amount of resources to get them in and out of a bus, to get them to the school, to essentially get them where they can interface with their peers. And that is a group that we call orthopedically handicapped. Many of them have an IQ near the norm, but they have no speech, or they have no communication and they have to use machines or some other way. And so that's the area where orthopedically handicapped has also increased. We have children who need what you would not consider in your mind educational, but their physical needs, to be able to educate the child. And so it's a combination of both. And this is an area where the schools and HHS and education department have worked closely to try and determine what's medical and what's educational. It's a very hard line to try and draw. But these are the kids that because of their orthopedic handicaps cannot get out or do the things they need to do to get an education. And that group in the past would probably have been in a regional center, 40 years ago. Today they're in the community, so it requires many more resources.
[LR283]

SENATOR LATHROP: Those folks with the orthopedic injuries or orthopedic conditions can also have the severe and profound problems, moderate problems, and mild problems cognitively? [LR283]

DR. BRUCE BUEHLER: Correct, and that's why, unfortunately, you're going to find as you go through developmental disabilities is like a big pot (laugh), it doesn't have a nice easy definition, other than the federal. But, yes, many of our children who are cerebral palsy to an extent can also have brain damage that is quite severe, and therefore require those services that are above and beyond. Where you get into institutional issues or issues of care is if a person cannot in any way support their own care--button a shirt, pull a shirt over, get out of bed. You're reaching a point where is that educational, or is that medical? And that's when you have to look at regional centers, because this is a...or nursing homes or whatever options your looking at, because it's so labor intensive to get each child taken care of. I'll give you an example. We have children we take care of that become so tight that you cannot clean them in an adequate way. And we actually have to do surgeries to release those so we can just clean the individual, keep them healthy, and well. That is not easily done in a community setting in many places. So there will always be that population who are more in the severe physical or severe physical and developmental range who will require specialized care.

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And you reach a point where specialized care, you need an infrastructure, and the infrastructure has to be large enough to support that group. If you do it on a one on one, it's very, very difficult. [LR283]

SENATOR LATHROP: One last question I have and then we'll ask you to address this for me. And that is can you give us an overview of how long those, if you can generalize for me, how long people with developmental disabilities typically stay in the family home or in the family setting? Do we run into them at some typical age? [LR283]

DR. BRUCE BUEHLER: I think that's a truly changing demographic. When I started in the seventies, I would say 10 to 20 percent of the children I saw at that time would eventually wind up in an institutional setting. Today I'd say that percentage is down significantly and probably not only less than 5 percent and so on. But in that group we're talking about very, very significant involved individuals who have both behaviors and physical. So the severity of the individuals who are not staying in the home is far greater than it was 40 years ago. And there really aren't a lot of options for the system, nor for the family. What we are seeing is a majority of individuals today with developmental disabilities are showing up within the 22 months or in the first 24 months of life. At about two years we are generally able to pick up. The Academy of Pediatrics now requires that every pediatrician screen children for developmental disabilities twice in their first two years, and they screen for autism twice in the first two years, and therefore we're finding these children that we may well have let go in the past. So it's a younger population. And those are almost always started in the community because you don't know their potential, you can't test a 2-year-old to really see where they're going to be when they're 15. And so they start there. When the system reaches a point where they no longer can care for them, it's usually in the early to middle teens when that individual is having such significant behavioral problems that schools have a very difficult time. And clearly when they reach adulthood and they become at a point where they not only can't function, but they can be dangerous to themselves or others, then you have very few options at that point. And so I would say that the general time is late teens and adulthood. [LR283]

SENATOR LATHROP: Very good. Thank you, I appreciate that. Does anybody have any questions? Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Dr. Buehler, you had stated behavior is a major issue. Does this behavior come from...you know, is it inherited or is it induced because of drugs and stuff like this? [LR283]

DR. BRUCE BUEHLER: Well, that's an excellent question. We'll take, for example, the most common behavior problem we used to address in institutional settings, was untreated phenylketonuria, PKU, which we screen for in newborns. Those individuals because of the buildup of this toxic chemical in their blood will begin to become so

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aggressive and so self-injurious, and their behaviors are almost impossible, they will actually tear their own skin, they will bite and so on, and that's clearly genetic, that one is clear. There is a group which has emerged, unfortunately, which is fetal alcohol syndrome, some cocaine and methamphetamine, although the community has done an excellent job in trying to incorporate where the behavior is damage. And no matter what we do the child is going to continue to have certain problems with priorities, with understanding consequences, not understanding what is required of them to fit in society, and that is brain damage. So there are both sides of that. And then in the genetic realm individuals may have a syndrome, but in general, and I'm sure others will testify far better than I, behavior management in most of those cases can reduce the behaviors quite significantly. But whether you can do it in a community setting, whether you have to do it in a regional setting is a really big issue, because sometimes it requires a huge amount. I have a young man we're taking care of right now through our center whose number one priority is to put his head through a window. He will run across a room, if he can find a window, and stick his head through it. Now that's self-injurious, obviously dangerous, and his behavior is at this point something we're trying to control. Very, very difficult individual. So many of your patients in regional centers have those kinds of behaviors that require two and three attendants just to keep them from injuring themselves. So I think your question is correct. Genetic...you have a...the one thing that always comes up, is it parenting? We spend a lot of time with parents and we work with them. And I would say in general, this is a generalization, most parents are not only committed, but they will do anything you ask them to do to help their child reach their max. But there's a certain point at which some of the behaviors can't be extinguished. [LR283]

SENATOR STUTHMAN: Thank you. [LR283]

SENATOR LATHROP: Senator Harms. [LR283]

SENATOR HARMS: Thank you very much for coming. I appreciate your expertise in this field. I have a couple of questions I'd like to ask you. Let's start with assessment. [LR283]

DR. BRUCE BUEHLER: Yeah. [LR283]

SENATOR HARMS: How do you actually determine what kind of assessment you're going to use? Do you just...you talk about drawing blood and from that you can get about 4,500 different approaches to, I guess, issues. What do you actually use for the assessment to start with this child? Do you actually draw the blood? Is that where you start? And then let's go...answer that one, and go a step further. [LR283]

DR. BRUCE BUEHLER: No, actually it's truly observation. [LR283]

SENATOR HARMS: Okay. [LR283]

DR. BRUCE BUEHLER: We will come in the room, I always bring a psychologist, usually a behaviorally trained psychologist, and we observe the child. We'll actually ignore the child for about 15, 20 minutes to see what they do. Then we'll go and look at both parents' histories, just to see if there is a history of developmental problems in the family. Then I'll do an actual physical exam. And I would say less than 10 percent of those I assess will I do blood on, because clearly they are delayed, but they had an injury at birth. I might do an MRI to look at their brain and see what was injured or I may, in some instances, just on the family pedigree, know that I'm dealing with a familial type of delay that's going to be part of the family. What I do next is send them into the school system. Put them into the school system through the early intervention program and I see them back in six months. And now I have objective reports from special educators, occupational therapists, physical therapists, speech therapists. And I have a better picture. And in general that winds up with us doing about 10 percent to 20 percent of the children that we see on some type of genetic testing. But 80 percent it's pretty clear that this child is delayed, needs services, and qualifies under the educational rules. I'm a doctor. I can send them to the school under other health impaired. But the school still has to certify them under their own rules, which is correct. So they will get a second eval., which is quite a bit more extensive than mine, to try and decide if they truly fit into the educational system. [LR283]

SENATOR HARMS: Now once that child has been placed in like, for example, into the school, then is it the school's then responsibility completely to take over the care of that child? Or are you still in that monitoring process, even though six months out...are you still involved, or what happens? [LR283]

DR. BRUCE BUEHLER: We stay involved and the reason is that most schools feel that the medical input is critical to them. If a child is losing skills or regressing, this is a great concern for schools obviously, they're going to send them back. So I see a lot of these children multiple times. Actually, I've now, in the last year, been to 22 graduations of kids I diagnosed at birth. And so you follow them in a long-term. Why a medical model? Well, the medical model, along with the psychological model, which is part of this, is a screening tool. It helps the schools to get started. Any parent who has concerns about their child can contact the school directly and the school will come out and evaluate them. [LR283]

SENATOR HARMS: Now let's say that the child, from your evaluation that the child needs to be placed in the Beatrice center, that they need special needs that our schools cannot provide, that a community-based program cannot provide. And a child is placed in to the center. Who's responsibility is it once that child goes in the center? Do you still stay in contact with the center? And the second part of it is, well, just answer that first. [LR283]

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DR. BRUCE BUEHLER: At this time, no. There are physicians in the center who become the primary care physicians. They will utilize me as a consultant on occasion to look at possible reasons that certain things are happening. But, no, it becomes essentially internal medical care with the people that are at the center. I will tell you today, in general, very few of the children we see are automatically set up to go to Beatrice. They're set up to go into the schools, and then we look at the record. And probably that's why we're talking teenagers and adults more commonly. [LR283]

SENATOR HARMS: If...what I'm really trying to get to then, once they're in the center itself another physician takes over. [LR283]

DR. BRUCE BUEHLER: Yes. [LR283]

SENATOR HARMS: Are you familiar how that works within the center? Because my concern really centers around follow-up and constant rediagnosis and that whole issue that's going. Because when you read the federal report here it's very clear that we've been unable to do that. It's very clear that we've not followed up in assessment. It's very clear that there are major issues here. And what I'm trying to get to, and that's what this committee is about is to center into that issue to determine what we have to find...what we have to do to resolve those issues. What do you see as an expert in your field as you view into that center in regard to that issue? [LR283]

DR. BRUCE BUEHLER: Having been a medical director at two training schools, I think it is a major issue for every training school to reassess. I mean it's very hard. It's easy to say, okay, we don't have the staff, we don't have the resources. But I believe today if we were looking for the ideal there should be consultation, there should be clinics at Beatrice with specialists to reassess individuals. And I set that up in Utah, and I set that up in Florida, and I believe it can be done here as a way of bringing in expertise. But no doctor has, none of us have all the expertise. But I think that a medical team approach, which includes behavioral, etcetera, is always helpful for the people who are doing the care and the treatment. [LR283]

SENATOR HARMS: Now the center is independent or integrated into the system? [LR283]

DR. BRUCE BUEHLER: At the present time, the way I understand it, and I do not know Beatrice well and I will defer to my colleague, it is not, as I understand it, a medical facility which is an open door, bring in medical and other expertise. They have their own system and their own individuals. And I don't work through that. I work through medically handicapped children's programs, through HHS, and that's how we do our clinics. [LR283]

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SENATOR HARMS: Let me go back to the community-based program for a moment. I know that one of the goals is for Beatrice to bring down the number of people that are in their control and place them into community-based programs. What do you know about Nebraska community-based programs? And are we really prepared to address those issues appropriately? And then are they staffed appropriately as your expertise views that? [LR283]

DR. BRUCE BUEHLER: Well, I will say at the present time, and again because of my own experience with families and patients, we are doing a superb job for up to 21. There is no question that the services are there. The schools will go overboard to help that individual. But then there is a cliff. And the drop-off is massive. If the individual does not have potential to transition into a more routine environment, we are far underserved with group homes, we need more. And one of the things I tell my parents when I diagnose their children at birth is, start thinking about what will happen when they're 21, because children want to leave home and there's a point at which children should leave home. And that system, no, is not adequate at this point. It's mostly private sector. It is not set up to adapt. There are many excellent programs out there, but they're probably well overloaded. [LR283]

SENATOR HARMS: Thank you very much. [LR283]

DR. BRUCE BUEHLER: You bet. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: Actually, I have a number of questions,... [LR283]

DR. BRUCE BUEHLER: Go ahead. [LR283]

SENATOR CORNETT: ...but they have a wide range here. In the beginning you said that early diagnosis of metabolic disorders, like PKU, has actually stressed the system more because of the early diagnosis and the children moving into the system earlier. Am I correct? [LR283]

DR. BRUCE BUEHLER: No, I may have misstated. [LR283]

SENATOR CORNETT: Because I...(inaudible)... [LR283]

DR. BRUCE BUEHLER: Yeah, that wrong balance, yeah. What I meant to say was earlier diagnosis of nontreatable conditions. [LR283]

SENATOR CORNETT: Okay, that was my... [LR283]

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DR. BRUCE BUEHLER: Yeah, has stressed the system. [LR283]

SENATOR CORNETT: Because if they're treatable then they actually don't move into the system, am I correct? [LR283]

DR. BRUCE BUEHLER: Exactly. [LR283]

SENATOR CORNETT: Okay. [LR283]

DR. BRUCE BUEHLER: And they were a significant PKU and untreated metabolic disease was a significant population that arrived in regional centers. [LR283]

SENATOR CORNETT: Okay. The next question has to do with autism. When you said that there was a 400 percent increase in diagnosis in the state of Nebraska, do you feel that is...is it the majority of better diagnosis techniques, or do you actually see...are we actually seeing a rise in autism itself? [LR283]

DR. BRUCE BUEHLER: In most difficult studies that we can come up with the CDC, and I've worked with them, feels that 150 children born today will have autism. And that figure seems to be fairly static right now. But that group went undiagnosed for probably ten years. So the 400 percent is better diagnosis. The actual increase is probably about 16 percent in actual numbers of children born today with autism that would have... [LR283]

SENATOR CORNETT: And you said worldwide that increase was approximately 14 percent? [LR283]

DR. BRUCE BUEHLER: Sixteen. [LR283]

SENATOR CORNETT: Okay, no, 16 percent worldwide. [LR283]

DR. BRUCE BUEHLER: Yeah, worldwide. [LR283]

SENATOR CORNETT: Got it. Okay. [LR283]

DR. BRUCE BUEHLER: And California, it was an 800 percent increase. [LR283]

SENATOR CORNETT: Because of diagnosis. [LR283]

DR. BRUCE BUEHLER: Because they opened up their diagnosis and the numbers just soared. [LR283]

SENATOR CORNETT: Under that question, has nothing to do with committee itself, but

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other bills we've had, you mentioned mercury. Because we've heard...we hear conflicting testimony continually on whether mercury-based vaccines are actually causing an increase in autism or if it's other environmental factors, or just simply early...different diagnoses. [LR283]

DR. BRUCE BUEHLER: It's a very difficult issue to answer. The vaccine issue may be easier only because we have data from Denmark, where they didn't have thimerosal in the vaccines. [LR283]

SENATOR CORNETT: But don't you only use thimerosal now currently in combination vaccines, like the flu vaccine, and regular children's vaccines don't have thimerosal don't have thimerosal in them? [LR283]

DR. BRUCE BUEHLER: Correct. [LR283]

SENATOR CORNETT: Okay. [LR283]

DR. BRUCE BUEHLER: And you can elect to get a nonthimerosal flu, actually. But what we found is we can't say, okay, mercury didn't cause it because mercury in fish have gone up, mercury in tuna have gone up. We don't know. We know today, in a recent study done, that we were part of the cooperative. There are chromosomal abnormalities which appear to account for some autism. But that person can have that chromosome abnormality, not show autism, and something in the environment kicks it in. Could be anything. And that's where all the work is going now is how can we look at the environment which may be...and the environment may well be in the womb. And so we've going to have to start even preconceptionally if we're going to make a difference. [LR283]

SENATOR CORNETT: Okay. And again that had nothing to do with this? [LR283]

DR. BRUCE BUEHLER: No, that's... [LR283]

SENATOR CORNETT: Back to Senator Harms's question when we were talking about whether we have the community-based services. When you're talking about someone that has a very self-destructive or violent behavior towards others, but right at the cutoff for what's considered a normal IQ or not, those people are very difficult to deal with. Having spoke to a number of people over the past few weeks, some of the people that are severely physically handicapped would be much easier to place in say, for instance, nursing homes or nursing care facilities, particularly as they age. When you mention we don't have the group homes available, is a group home even an appropriate setting for people that need two on one or three or one care? [LR283]

DR. BRUCE BUEHLER: Probably not. There you reach an infrastructure issue. You've

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got 24/7, you need people who are trained in children who are abusive to themselves or others. That takes a great deal of expertise. So I don't know that a group home is going to solve that issue. What we are trying to do, and I think all of us are all in the same boat trying to pick out those that we may be able to modify behaviors to where they can live in the community. But there's a certain point at which you may not be able to. And when we talk about self-abusive, we're not talking about just hitting your head. [LR283]

SENATOR CORNETT: No, I know. [LR283]

DR. BRUCE BUEHLER: We're talking about severe self-abuse. [LR283]

SENATOR CORNETT: Well, that brings me to one other question. And it has...because I deal with a constituent who I've been working with now for four years. She has an adopted daughter with special needs that was born of a severely drug addicted mother. She has above average IQ, a significantly above average IQ, but she's unable to differentiate between reality and fantasy. So the school, for instance, has pulled her off the ledge because she thinks she can fly. There...she sees a cartoon, she believes that that is reality. They have no idea what to do with this child as she's moving into her teenage years, because she's very large girl. Because they're diagnosed as psychiatric issues, but normal IQ, what happens to those people that truly have these disabilities? Because we all know that we are not equipped to deal with mental illness at this level in the state. I mean we don't have the facilities. [LR283]

DR. BRUCE BUEHLER: One of the important things in this case would be probably the word mental illness doesn't apply as much as brain damaged. [LR283]

SENATOR CORNETT: Brain damaged, exactly. [LR283]

DR. BRUCE BUEHLER: That's right. And so... [LR283]

SENATOR CORNETT: And that's where we're running into a problem. [LR283]

DR. BRUCE BUEHLER: And there you're talking about, okay, I can teach this child to act good in a certain setting. Okay, if it's the same setting every day, if the plates don't change color, if you get up exactly the right time, you go to school at exactly the right time, I can do okay. But as soon as you change my routine I don't know what to do. [LR283]

SENATOR CORNETT: That's very bad for this girl, yeah. [LR283]

DR. BRUCE BUEHLER: Yeah. And so those are the population that will need other services that we have no idea today how to provide because their impulsivity, their lack of consequences, their inability to judge what's right or wrong easily, not their bad, they

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just don't understand somebody says go steal that car, or take that car and drive it over and we'll all run off. You want to please your friends and you don't have the concept of what you've just done. These are going to be our most difficult individuals because of the comment that you made, and that is they are generally intellectually intact. [LR283]

SENATOR CORNETT: But that's...and that's where we're running into the problem is the school is saying this girl needs to be placed in an institutional... [LR283]

DR. BRUCE BUEHLER: Right. [LR283]

SENATOR CORNETT: ...of some sort. But none of...there is no place really that we've been able to find for her, working four years now, because she is IQ-wise fairly normal. But she is still brain damaged. [LR283]

DR. BRUCE BUEHLER: Unfortunately, she's wise enough to also talk her way out of many things and have an excuse for every reason that she did things. This is a population we are facing that is very difficult. This is the fetal alcohol, fetal drug effects. [LR283]

SENATOR CORNETT: I was going to say we see that increasing because of the drug abuse and the alcohol. [LR283]

DR. BRUCE BUEHLER: Yes, and I really think not this committee, but we need to continue to look at ways preconceptually to try to decrease the expose rate. Because it's not something we ever fix. [LR283]

SENATOR CORNETT: No, it's not, but... [LR283]

DR. BRUCE BUEHLER: It's not going to go away. [LR283]

SENATOR CORNETT: But that's a separate issue, trying to prevent it. What...do we need more programs for people like this? Do you see this in a community-base, or are we going to end up having to do something like a state facility for these children? [LR283]

DR. BRUCE BUEHLER: I think it can be community-based and it will take a situation in which it's a regimented day. It's not cognitive, it's not trying to teach them reading and writing, it's doing a task that's important, that they've contributed. But that the limits are set continuously. So these are more behavioral units as opposed to institutions. And that behavior has to be maintained at home, or a group home, wherever it is, and there has to be consistent...in general, children who are damaged by drugs and alcohol do best when everything is consistent, they have a routine. That's what we need to set up. And that at the present time isn't a major issue with our group...our work systems.

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[LR283]

SENATOR CORNETT: So as you see us progressing forward as a society, we probably need to look at evolving our system from where we were in the past with metabolic disorders to brain damage from drugs and alcohol and (inaudible) different systems. And we're not equipped to deal with that yet. [LR283]

DR. BRUCE BUEHLER: Correct. I think we have the intent to deal with it, but there is no agency, no group tasked to do that, it ends at school. [LR283]

SENATOR CORNETT: Thank you. [LR283]

SENATOR LATHROP: Very good. Senator Adams. [LR283]

SENATOR ADAMS: At one point during your testimony you said that you've run clinics throughout the state. [LR283]

DR. BRUCE BUEHLER: Yes, sir. [LR283]

SENATOR ADAMS: The problems are everywhere. What about the services? Do we see great...do you see disparities in services provided from one end of the state to the other? [LR283]

DR. BRUCE BUEHLER: Excellent question. I would say that our state is probably up in the top five in the country in getting services to people, especially in rural areas which are very difficult. But we run into the same issue that you'll be dealing with, with regional centers--staffing. And so although the systems are good and the people in the systems are excellent, the number of needed professionals is still shy essentially west of Lincoln. We start to run into one speech pathologist trying to cover 250 miles, and ten speech pathologists sitting in the city. And that's where we run into difficulty. Is the quality good? Whatever they can deliver it's superb. The children get excellent services. But I have a young lady I've worked with now for 25 years who is an OT. And her average driving a year, just to see her patients is 55,000. She has a trunk, thank goodness they make a big Buick, she puts all the stuff in it, and she heads out to the road. She's out on the farm, she's out in the rural areas. She can only go so long. So I think there we have a major issue. And I'm sure the ESUs would comment on this and the school systems. As much as they can give their professionals, they will give top flight service. But it's staffing, which is going to be an issue in any of these. [LR283]

SENATOR ADAMS: Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

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SENATOR GAY: To follow up with Senator Adams' question then, you had said several times the schools are doing a great job in this area. But would that go so...are schools are differently providing services, or metropolitan areas doing a, I would say a better job, but how do we address that? Are they teaming up and how do they provide all these services that you say they're doing such a good job with? [LR283]

DR. BRUCE BUEHLER: Well, I will say two things. The metropolitan area is a different system because you have school districts who essentially create their own programs and have the personnel necessary, in most cases, to deliver. That's one system and that works well in Lincoln and it works well in Omaha. When you get west of Lincoln, now you're looking at the ESUs and the local school districts. And I am always surprised and amazed at the amount of resources that these counties put into their schools to develop equivalent programs. But they use the ESU because the ESU can give them an OT or a PT, if they couldn't hire themselves, on a full-time basis. And so I think the western part of the state had adapted immensely well to the large spaces to cover. The metropolitan schools have one major issue and that's transportation. Even though we're in a single unit, getting kids to the school is tough. Whereas on the western side, an awful lot of the families they just know they're going to have to bring the child in, or the school has already figured out a system. So I would say if you were to try to do a comparison across the state, you would find very little difference other than the number of professionals available. I think that's where we run into problems. When I go out to Imperial, or Ogallala, and I'm working in those areas, one of the things I always ask is, if I recommend five days a week of speech, could anybody do that? They've got one (laugh) speech pathologist, she's going to do five days a week with that child and nobody else. So you have to be realistic. On the other hand, we know from our own data that the number one caregiver in the school setting is the parent. So you train them, and they learn how to do what you could do with their child, and they give the care. And that I find exceptional in this state. Families take on the responsibility, they do the physical therapy, they do the occupational therapy, they work with them. [LR283]

SENATOR GAY: Okay. [LR283]

SENATOR LATHROP: Any other questions? I do want to follow-up on those, because I'm listening to you say that in Nebraska we do very well right up to age 21, and then there's a cliff. You've also...so let me talk just about the school age kids, if I can or those that are...that get services because the schools have a duty to provide that service. [LR283]

DR. BRUCE BUEHLER: Sure. [LR283]

SENATOR LATHROP: You said that we are...that we don't have as many speech pathologists, for example, out in greater Nebraska as we do in Omaha. Notwithstanding that, are we still doing a good job for those school age kids? Is that the point you were

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making? [LR283]

DR. BRUCE BUEHLER: Yeah. I think the fairness here is that the philosophy as you go farther into greater Nebraska is the parent is an active caregiver. And so a speech pathologist may come up only once a month, but they're going to go over that child with you, show you how to do it, if by chance we can have both family members there...many of my therapists will go at night or on weekends. And what they do is make the family, the caregiver, with the right knowledge. So it's a practical way to approach it. We did a study several years ago looking at how much physical therapy a child needs. And once a day, once a week, once a month, the outcome was essentially how much the parents did. [LR283]

SENATOR LATHROP: So if they have to go through range of motion, you can teach a parent to do a range of motion where that... [LR283]

DR. BRUCE BUEHLER: Exactly, and the parent will actively do it. And they've got 16, 18, 24 hours to do it. I have them do it while the child is bathing, or when the child is relaxed, or just before they go to bed. I can't get a therapist, obviously, to come and do that. So a lot of it is giving you the services, but also expecting and I think getting parental involvement, which is critical. [LR283]

SENATOR LATHROP: If we take that period of time after the cliff, child gets to 21 years, is your opinion still the same that out in west of Lincoln that the services are still adequate to meet the needs of that community, that developmental disability community? [LR283]

DR. BRUCE BUEHLER: It gets much more sparse for reasons of settings. You know, you've got to have a job, a vocational program, you've got to have a community support, you've got to have probably a group home nearby, or someway, or the families have to be able to transport or get transport. There isn't as dictated a treatment plan as there are through the schools. It's very set, we know what it is. So I would say organizationally maybe the biggest issue, but on the other hand, there are many superb group homes, superb activities for individuals. And I don't mean activities, I mean jobs, reasonable and relevant jobs. But it's probably not sufficient for the population that's aging. I think doctors have done a good job in longevity, but that will include our population. And we have to be ready for that. [LR283]

SENATOR LATHROP: Okay. So let me go back to my question, if I can. And that is, do we see a difference then in the resources that are available to a 30-year-old man with special needs that's in Omaha versus the same person or a contemporary in Scottsbluff, or Imperial, or Ogallala? [LR283]

DR. BRUCE BUEHLER: I would say in general we find the same lack of sufficient

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services in both settings. They're not there, not intentionally, it's just very difficult to provide in those settings. [LR283]

SENATOR LATHROP: All right, thank you. Any other questions? Seeing none, thank you very much for coming down today. It's very helpful. [LR283]

DR. BRUCE BUEHLER: My pleasure. [LR283]

SENATOR LATHROP: Our next witness is going to be Bruce Mason. And that will take us really to the second piece or the second item on our agenda, which is the legal requirements the state has with respect to care for the developmentally disabled. You've filled out a sheet? [LR283]

BRUCE MASON: Yes, I have, Mr. Chairman. [LR283]

SENATOR LATHROP: All right. You can set it in the box there, that would be great. And if you could start with your name, spell your last name for us, and give us your address, we'll have you share some information with us. [LR283]

BRUCE MASON: It's Bruce Mason, M-a-s-o-n. I am the litigation director for Nebraska Advocacy Services, located in Lincoln, Nebraska, on 13th and N Street. I have been a practicing attorney specializing in representing individuals with disabilities and their families for longer than I would like to announce publicly, some 35 years or so. And I would...want to thank the Chairman and members of this committee for this opportunity to discuss matters that I consider of extreme importance for our citizens who are developmentally disabled and their family members. And with a significant amount of humility, I hope I can aid you in this significant endeavor. Let me start off by giving a brief story. Over three decades ago, in 1972, a much younger lawyer with a lot more hair, just two years out of law school met with parents who...and family members who had family members at the Beatrice state home, back in 1972, and who pleaded with him to help them with the conditions at the home. Their stories of staff shortages, neglect, lack of meaningful treatment programs, unexplained injuries suffered by their sons and daughters gave him little chance to refuse their pleas. They had at that time lost hope and felt abandoned by state officials, back in 1972, who were responsible for the care of their sons and daughters. That young lawyer, on September 28, 1972, some dates you never forget, filed a class action premised upon the legal argument that the due process clause the Fourteenth Amendment protected those at Beatrice from physical and psychological harm. And that if they were going to be confined there in the custody of the state and deprived of their liberty, they must receive treatment. In 1972, at the time that that class action for residents at the Beatrice state home was filed, that was literally an argument of first impression in this country. It had been accepted only by one other federal judge, and that was what they call a mountain Republic judge in the northern district of Alabama, Frank Johnson, who would later head up the FBI, who had

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ruled in a case, Wyatt v. Stickney, that persons confined in a mental institution with mental retardation had a constitutional right to treatment. And he was in the process of formulating the extent and the parameters of that treatment. Well, this young lawyer, back in 1972, with the assistance of the newly formed section of the Office of Special Litigation within the Civil Rights Division of the Department of Justice, they reached an agreement, in Horacek v. Exon, with Nebraska's Attorney General, then Paul Douglas, and Governor James Exon's private attorney, Norman Krivosha, who would later become the Chief Justice of the Nebraska Supreme Court. And this settlement agreement was approved on October 31, 1975, by United States District Court Judge Albert Shatz, in consent decree. That consent decree recognized the constitutional rights of the citizens at Beatrice to be protected from physical harm and psychological harm, and to have a right to treatment or the term of art is habilitation with individuals with developmental disabilities. More than, you know, three decades later, that same lawyer, now older, thinner on top, and thicker in the middle, appears before this committee that has an opportunity to finally fulfill completely that promise that was made by state officials in 1975. So as that the citizens at the Beatrice State Developmental Center will have their full constitutional rights protected. What was a novel and innovative proposition in 1972 and 1975 is now, in 2008, settled constitutional law, not subject to question. And those mandates of that constitutional law are unequivocal and inescapable for the state of Nebraska. The state is clearly obligated, constitutionally obligated to protect its citizens at Beatrice under the clear mandates of the Fourteenth Amendment, to protect them from physical harm, psychological harm, unnecessary restraint, and that restraint means both physical restraint, and chemical restraint, or the use of psychotropic drugs, and neglect, and to provide them with treatment or habilitation consonant with their individual needs. There is no exception to this clarion call of these constitutional mandates for the state of Nebraska which resonates from the pronouncements of recent United States Supreme Court decisions, as early as 1982. Hopefully that I and esteemed counsel, Ms. Jodi Fenner for Health and Human Services, will not bore this committee with the nuances and subtleties of constitutional law, but we'll attempt to give a general framework or outline so that you can understand the three primary duties that impact on the individuals that reside at the Beatrice state home and the duties that Nebraska assumes when a person with a developmental disability enters the gates at the Beatrice State Developmental Center to live. The first and primary most important duty, and it's not really...requires rocket science, is the duty of protection. That's the easiest way to say it. I mean if you consider one of the seminal amendments of this government, which is the Fourteenth Amendment, enacted as a result of the Civil War, it's the duty of protection, equal protection. The United States Supreme Court, in 1982, in Youngberg v. Romeo, placed its constitutional imprimatur, its approval on that argument that was raised in Nebraska in 1972. The persons...and they held that persons with a developmental disability who reside in state facilities, such as Beatrice State Developmental Center, have a constitutionally protected liberty interest in safety. The court further held that the state has an unquestioned duty to provide reasonable safety for all of the residents within the institution. Included within

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the meaning of that duty of protection of reasonable safety, the residents must be protected from unreasonable restraints, as I said before. And that includes chemical and mechanical. And also within this umbrella of this duty to provide reasonable safety, the state must provide medical care, appropriate, adequate medical care, food, shelter. And furthermore within this duty to protect they...the state of Nebraska and its officials must provide reasonable safety so that the person that lives there is not verbally assaulted, physically assaulted, abused, humiliated, or his medical and psychological needs ignored. Our own state statute, 83-1202(8), echoes that primary responsibility of protection. And the clear intent of this body is unequivocal in that. And I quote from that section, the first priority of the state in responding to the needs of persons with developmental disabilities should be to ensure that all such persons have sufficient food, housing, clothing, medical care, protection for abuse or neglect, and protection from harm. This is an affirmative duty. And this affirmative duty, I submit to this committee, is very significant. It's an affirmative duty and an entitlement that individuals with developmental disabilities that reside at the Beatrice State Developmental Center have. And it's enforced by a federal court because of that special relationship that the courts have recognized between the state and a vulnerable person with developmental disabilities. We must remember, generally, federal courts have held that the constitution is a negative charter. It only requires the states to refrain from acting. This, on the other hand, is at the other spectrum and says, there is now an affirmative duty to protect. And this affirmative duty arises under the constitution and that special relationship that is created when the state assumes total custody and control of an individual that is vulnerable and has a developmental disability. This affirmative duty received its, once again, judicial blessing from former Chief Justice Rehnquist in DeShaney v. Winnebago County Department of Social Services that explained that affirmative duty arising. It's very simple that when an individual's liberty is restrained, or his or her freedom of action is restricted, that restriction of an individual's freedom of action, which occurs in an institutional setting such as placement at Beatrice, that triggers the liberty clause of the due process. So, therefore, the second prong of that special relationship or that duty to protect arises from a very fundamental concept in the law that when the state, by its officials, place a vulnerable person, such as at Beatrice State Developmental Center, in danger of physical or psychological harm because of inadequate staffing, inadequate training, or inadequate supervision, that that duty to protect is breached. So it's the inadequacies or the neglect that in fact places the vulnerable person in a more vulnerable position that creates the duty, the second constitutional leg or constitutional right. And by the way, I should add also that the restatement of torts, Sections 3-14, 3-19, also, which is well established, also well recognizes the special relationship that when you take custody of a person, that you therefore create a duty to care appropriately. And that if you fail that duty, either by omission or commission, that in fact you're responsible for the consequences. So the special relationship really encompasses and sort of adds depth to the constitutional duty of protection. The second primary duty that the state assumes for those individuals that reside at the Beatrice State Developmental Center is that those individuals must receive training or

habilitation or treatment. The United States Supreme Court, in the Youngberg case, addressed that in 1982 and agreed when they said, persons with developmental disabilities have a constitutional right to minimally adequate training. Specifically the minimally adequate training, the court acknowledged, required by the constitution is such training as may be reasonable in the light of the institutionalized person's liberty interest and safety and freedom from unreasonable restraints. That's a mouthful. Essentially what it means is that the essential component of habilitation really, or treatment, for a person with developmental disabilities is a regular systematic provision of activities, programs designed to help them to develop new skills, and maintain skills that they've already learned. That may go from the gamut of self-help skills that we would...we have all seen. And for those of us that have had children and raised them, from learning how to dress, toilet, teeth brushing, feeding, all the way up to more refined skills. But it's the gamut, because every individual at Beatrice Developmental Center has the ability to have some level of skills. Therein lies what the treatment must focus on that individual ability to develop those skills to the best possible extent. And the test, and this is not an impossible task that the courts place on the facility or state officials, such as at BSDC, but the test is whether or not those officials, those individuals at BSDC have provided adequate minimal levels of constitutionally required care depends on if, and this is the crucial element and this is really important, on if that facility's practices substantially depart from generally accepted professional judgment. If the facility's practices substantially depart from generally accepted professional judgment. That's the Youngberg court speaking. How do we achieve evidence that those practices either comport with or depart from, you know, professional...a substantial departure from accepted professional standards? We find that neither the opinion of other qualified experts, or violations of national regulatory standards or guidelines. So either similarly situated experts say, in my opinion this is improper and this is a substantial departure, or guidelines. Regulatory standards in fact set out the professionally accepted standard or care. And I'm sure that every member on this committee has had at least a passing knowledge of the Centers for Medicare and Medicaid Services volumes of reports that have in fact come in and surveyed the facility at Beatrice. Those are the national standards that determine professionally accepted standards of care. All right? Because it's an ICF/MR, which simply means an Immediate Care Facility for individuals with Mental Retardation. So therefore what are those standards? That...those standards give us the road map, they give us the blue print to say, are you meeting the standard of either protecting the residents from harm, or are you meeting the blueprint for treating them and habilitating them? Okay, they set up standards to provide adequate staffing levels, and to ensure the provision of active treatment. It's very important because those standards require active treatment to reduce dependence upon drugs and physical restraints. As Dr. Buehler commented on earlier that behavior management is a crucial component in order to shape behavior that's appropriate and desirable. And those behavior management programs are an essential element of that. In particular the CMS standards found, for those that have an interest in the arcane, 42 C.F.R. 483.420(a)(5), and only the federal regulation can go on and on, requires that

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the facility ensure that clients are not subjected to physical, verbal, sexual, psychological abuse. They also require the facilities to provide sufficient direct care staff to manage and supervise the residents to ensure that the clients are provided active treatment to reduce dependency on drugs and treatment. Adequate staffing becomes crucial. Now the third and most recent duty of the tripartite duty that the state of Nebraska assumes when an individual goes into the facility is the duty of integration, inclusion, or it's referred to often as the integration mandate. And that arises not from the constitution as much as from the federal Americans With Disabilities Act of 1990, the ADA. State simply, Justice Ginsburg, of the United States Supreme Court, in 1999 in Olmstead v. L.C., held that undue institutionalization of confinement of persons with mental disabilities, as Dr. Buehler said mental disabilities is a legal term, qualifies as prohibited discrimination by reason of a disability under the public service portion, or Title II of the ADA. What does all that mean? Justice Ginsburg noted the extensive history of isolation and continued segregation of persons with disabilities and recognized that unjustified institutionalization is a form of isolation that is a prohibited discrimination for the reasons as follows, first,... [LR283]

(EQUIPMENT MALFUNCTION -- SOME RECORDING MAY HAVE BEEN LOST)
[LR283]

SENATOR LATHROP: We have the audio part all worked out, so we're ready to continue with the testimony of Mr. Mason. [LR283]

BRUCE MASON: Thank you, Mr. Chairman, members of the committee. I was discussing what Justice Ginsburg had written in the Olmstead decision, that unjustified institutionalization and isolation is a form of discrimination. And she really based that conclusion in violation of the ADA upon two primary reasons, and that's first that continued institutional placement of persons who can handle...and the operative words are "who can handle and benefit" from community settings perpetuates unwarranted and stigmatizing assumptions that the person so isolated are incapable or unworthy or...of participating in a community life. This is clearly analogous to discrimination based upon racial or sexual stereotypes that's prohibited by law. Secondly, her other reason was that confinement in an institution, a total institution such as Beatrice State Developmental Center, severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. What all this means, the bottom line for the state of Nebraska, is that the state with its professionals must conduct reasonable assessments in determining whether a person at Beatrice is either, one, able to handle or, two, can benefit from community settings. If, based upon that assessment and that answer to either one or two is yes, that resident is a qualified individual within the meaning of the ADA, and the duty to integrate him or her in the community arises. Now this duty to integrate...yes. [LR283]

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SENATOR LATHROP: Can I interrupt you just a second? Pull that mike a little bit closer and then I'll ask you to speak up just a little bit more so everyone can hear. Not everybody can. [LR283]

BRUCE MASON: Okay. [LR283]

SENATOR LATHROP: All right? Thanks. [LR283]

BRUCE MASON: So this duty to integrate has an additional qualification under the federal regulations and this becomes important because this clouds that clear mandate somewhat, and it also puts state officials in somewhat of a conundrum, and let's talk about that briefly. And that federal regulation found at 28 C.F.R. 35.130(9)(e)(1) 1998 reads: Nothing in this part shall be construed to require an individual with a disability to accept an accommodation which such individual chooses not to accept. The regulations further read that persons with disabilities must be provided with the option of declining to accept the particular accommodation, and what those regulations mean by "accommodation" is placement in the community setting. So that...those regulations impact somewhat on the duty to integrate in that they have an option of declining. So here's the problem the state faces as they attempt to implement this duty to integrate. Most of the residents at the Beatrice State Developmental Center have guardians that have been appointed by the respective county courts throughout the state of Nebraska. Many of those residents are unable to articulate/express their desire to live in a community. Many have been there for decades, 20, 30, 40 years. So what happens when a guardian objects to the placement of an individual that the state officials and professionals have assessed as either can benefit from or can handle community setting? So the simple question is then posed: May the opposition by a guardian to community placement of a resident who, in the assessment of the state's professionals, can handle or benefit by placement in the community circumvent or thwart the integration mandate of the ADA? That's the crucial question and the answer is a qualified "no." And I suggest, respectfully suggest, that it's a qualified "no" because a guardian's desire or wish is a significant and important factor, but it is not the sole controlling factor that would determine the ultimate placement of that individual to fulfill the integration mandate of the ADA. Ironically, we, in the lawyers that drafted the consent decree back in 1975, in Horacek v. Exon, anticipated this very problem. And Sections 21 and 22 in the Horacek settlement agreement consent decree really provide, like Ariadne's thread, a way out of this labyrinth for you, being Phaestus, to mix my mythology here. Because those sections of the agreement establish procedures and a hearing process which met the constitutional due process requirements for community placements of an individual qualified, and whose guardian or family member objected. These sections of that agreement entered into with the state...by the state in 1975 no longer...it has lapsed, but they become relevant and germane to the current problem that state officials face as they attempt to place people that are qualified into the community and meet the integration mandate. Let me read that Section 22 because I

think it's highly pertinent to the discussion at hand: Objections by parents or legal guardians shall not be used to preclude placement of any member of the class in any program or facility which is indicated by proper evaluations to be in the therapeutic interests of such member of the class. A hearing which meets the basic standards of due process, as defined herein, shall be held to ensure that such objecting views of parents and guardians are heard and that the placement to be made is in the best interests of the members of the class, commensurate with his or her needs and his constitutional rights to receive adequate care and habilitation in the setting least restrictive of his personal liberty. Section 21 defines the basic standards of due process as: a due process hearing shall include a clear and concise, understandable notice to the person with the developmental disability and his parents or legal guardian of the hearing, and at least...at least two weeks prior to the hearing to determine placement out of the facility; (b) Appointment of competent counsel to represent the person with the developmental disability; (c) the presence of the person with the developmental disability and the guardian or parent at the hearing; the presentation of clinical evidence in either support of the decision to place out or to retain in; (e) the opportunity to cross-examine all witnesses and present evidence; (f) findings in writing on the basis of clear and convincing evidence; and (g) the right to judicial review of that decision. Therein lies the ability to finally resolve this issue of that the guardian, in and of themselves or herself or himself, should not be able to obstruct/impede the constitutional mandate of the Americans with Disabilities Act for that individual that's a qualified...qualified meaning can benefit from or can handle community placement. So in conclusion, those individuals or persons that are citizens who live at the Beatrice State Developmental Center have a judicially enforceable right or entitlement from the state of Nebraska. This entitlement is to be protected from physical/psychological harm; to be free from unnecessary restraints, either chemic or physical; to be protected from abuse, physic or verbal; and to be provided with appropriate medical care and not neglected. Second: to receive active treatment or habilitation based on their individual needs with the appropriate and accurate assessment of their needs, the development of programs by professionals and staff, which are implemented by adequate numbers of appropriately trained and supervised staff members. And finally third: to be integrated in community settings if either, after assessment, they are deemed either able to handle or to benefit from those community programs, and due process hearings have been held if in fact guardians object to the recommendations for community placement. Finally, I would like to thank the Chair and the committee for this opportunity to discuss. I truly apologize if I've stayed too long on a matter which has occupied over, you know, 35 years of my professional life as a civil rights lawyer in the state of Nebraska. And if there's any questions, I'm more than willing to attempt to try to answer them. [LR283]

SENATOR LATHROP: Very good. Senator Harms. [LR283]

SENATOR HARMS: Thank you very much for coming. I appreciate you bringing your expertise to us. Since 1972 to now, I'm sure you probably have read the different

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reports that we've had and the issues we've had at Beatrice. [LR283]

BRUCE MASON: Yes, sir. [LR283]

SENATOR HARMS: It's pretty clear to me that we have been...and I'm no attorney, but just reading this last report it's pretty clear to me that we're in violation of an awful lot of things that you've just brought up, and there's an awful lot of liability laying out there in regard to this center and what's occurred. Because if the report is accurate, it's very clear to me that that's a major issue that we ought to be concerned about here. [LR283]

BRUCE MASON: I would agree. I also was one of the primary authors of our report which preceded the report by the Department of Justice, in December of '07 we issued that report, and there is no question about it. And, to be honest with you, Senator, and I'm going to steal a line from a singer that I have followed throughout the years, that you...Bob Dylan, you don't need to be a weatherman to know which way the wind's blowing, and that's absolutely right. There's no question about that. And it is not that there is malevolent individuals there but the problems that have existed have existed over a period of time and we've engaged in a dance. CMS comes in, they evaluate and they find fault, they find inadequacies; a plan is developed, they go away. And they come back and say, you promised to do it, you promised to do it, but it wasn't done and now you're in violation. This has gone on. I mean the issues that I dealt with in 1972 have resurfaced like the Phoenix from the ashes of that consent decree in 2007-2008. [LR283]

SENATOR HARMS: Well, thank you very much. That was my observations and, you know, quite honestly, as I look at it, it's truly an embarrassment and I think it's time to fix this thing. Thank you. [LR283]

SENATOR LATHROP: Senator Adams. [LR283]

SENATOR ADAMS: The criterion that you were talking about earlier that applied to Beatrice, we heard in earlier testimony, as I'm sure you did, too, that from 0 to 21 the schools are dealing with a lot of this. Do these same kind of legal requirements and responsibilities fall on the school that fall on state institutions such as Beatrice? [LR283]

BRUCE MASON: With the passage of the Education of all the Handicapped Children, later to be turned into the Individual (sic) with Disability (sic) Education Act, which is the mandate of special education, there are obligations that fall within the state or within the school districts. An example: a school district is obligated to provide a free and appropriate education to an individual with a disability under IDEA, I-D-E-A--it's now been changed but for the purposes of this discussion. That's up through the age that Dr. Buehler testified to earlier. And if they can't provide that in the school setting then they must provide it in an alternative setting, and the state of Nebraska funds that federal

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mandate also and assists the school district. So at one time there were individuals that were of school age at the Beatrice State Developmental Center. Instead of their going into the Beatrice school system, which would be where BSDC is located, they would be educated in a segregated setting on the grounds of a school even though they should have been educated the Beatrice School District, paid for by the Millard School District if they felt they couldn't handle it. Now I don't know if I've answered your question. I'll go back to it and try it again if I haven't fully answered it. [LR283]

SENATOR ADAMS: No, I think you have, but I guess I was wondering, too, more specifically, you talked about the protection, the safety, those kinds of things. I'm assuming that the schools are held to some equivalent standard. [LR283]

BRUCE MASON: Somewhat equivalent. The reason that there is a distinguishing characteristic in the case law that's developed is that they, the courts, have in fact said that you don't have full total custody of the person. It's that custodial confinement that triggers the special relationship and also triggers some of the constitutional obligations under the Fourteenth Amendment liberty clause. So schools don't have total confinement of the individual. Now ordinary negligence standards--you should have known, you didn't act when you, you know, you should have acted--that commission/omission would apply, but not constitutional standards. However, those programs in the community that provide residential 24-hour service, in fact, those constitutional requirements would attach to those individuals that are in those programs. [LR283]

SENATOR ADAMS: Thank you. [LR283]

SENATOR LATHROP: Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Chairman. Yes, Bruce, are we under the same obligation? Say we place a client or resident in community-based and the community-based is not doing the job, and that person gets abused or hurt. Are we at risk there too? [LR283]

BRUCE MASON: It would be my position, and I think the law would support that, yes, if, in fact, you place that person in a residential setting within the community, because that, you know, you cannot contract away your responsibility. And one of the...you know, the Achilles' heel of all of this and that you folks in this committee are somehow, in your Solomonlike wisdom, are going to have to deal with, and I don't know, is the fact that we have developed a dual system of care instead of a unitary system of care. So we have Beatrice component here and then we have the community programs, like they're separate universes. What should be simply developed is a unitary system from cradle to grave based and each according to his or her needs, and where there's a spectrum, where each one has a role and a part based upon the evaluation needs assessment of

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that individual as they progress through their lifetime. And I know this is a major concern for parents that take, you know, their responsibility to raise their son and daughter with a disability in their home and to keep them there. As they start to age, as the inevitability of that process goes on, what am I going to do to Billy, to Susie when I'm gone; what's going to happen; where is that? And because of the hodgepodge mosaic that we've woven, instead of the unitary system, that we can't answer that effectively and that creates uncertainty and we fail to meet our obligation as government, which is the primary obligation, as you well know, to protect those that can least protect themselves. [LR283]

SENATOR WALLMAN: And on this assessment issue, who is all involved in that? Just state officials? The doctors? The local regional centers? How do we say it's misdiagnosed or something? You know, somebody has to come back and we have a waiting list to get in there. Who assesses all of those? [LR283]

BRUCE MASON: You know, that's a great question and we back in '72 attempted to address that by having individuals representing the community services, representing the state, and parents, and professionals from the university that would be considered not involved in the process, those, that was the assessment component so that there would be an objective standard developed so that nobody could say, you know, just the state's officials are doing an inadequate job or the community people are doing it in such a way because they don't want to take...they only want to take the high draft choices, the blue chipper, so to speak, you know, the five-star recruits; you know, they don't want to take the walk-on that causes problems, to use that football analogy. So that's really crucial. That assessment process can be done and is really the heart and soul, the foundation of the overall development of this unitary system. [LR283]

SENATOR WALLMAN: Thank you. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: The trend currently is to move to community-based, basically, and that's what we've been hearing, that a lot of these people need to be moved to community-based residential care. When you talk about one system, are you talking about a state managed system from birth to grave, basically? Or are you talking about combining services with the private sector, as we currently are? When you talk about one system, how would you achieve that? [LR283]

BRUCE MASON: What I'm talking about...and that's an excellent question, Senator, because it sounds a little bit socialistic and it wasn't meant to be socialistic at all because I'm quite the opposite part of that spectrum. But what I meant was that was a coordination, the belief, the paradigm that it would a unitary system based upon the individual's needs and abilities, as those needs and abilities change, involving private,

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for-profit, not-for-profit, state contracting, but where the rights would flow with the individual, the services would flow with the individual there. It would be... [LR283]

SENATOR CORNETT: Okay. (Inaudible) [LR283]

BRUCE MASON: It would be coordinated. There would be a plan. [LR283]

SENATOR CORNETT: That's not the way it sounded originally. (Laugh) [LR283]

BRUCE MASON: And I apologize. I did not articulate it very well and I didn't want to mislead the committee. But it is...and I use that term "unitary" because Beatrice has a component part. Even the regional centers, the Lincoln Regional Center, they all have a component part. We now heard Dr. Buehler and I think you asked the question, rightly so, what about this individual that has this mental illness that developmental disability services say, well, no, this is a mental illness, this is this, and they get shuffled back and forth? You know, it's like the "SODDI" defense--some other dude did it. You know, that's what we're trying to avoid, that, so that it's not the label that's important, it's the assessment. [LR283]

SENATOR CORNETT: The assessment. [LR283]

BRUCE MASON: And then we can plug in the services along the road. [LR283]

SENATOR CORNETT: When you talked about that even if we are moving to community-based services, that doesn't...the contractual agreement does not remove the liability of the state. Correct? [LR283]

BRUCE MASON: If, in fact, the state exercises some degree of supervision and requires certain standards to be met, yes. And I can say that because as...in my past, one, I was general counsel for one of the community programs, ENCOR, which is up in Region VI and encompasses the Dodge, Washington, Sarpy, Cass, Douglas area, and in fact there was still a state obligation. It's just not a question of handing over bucks and saying... [LR283]

SENATOR CORNETT: Okay. [LR283]

BRUCE MASON: ...do something. [LR283]

SENATOR CORNETT: So just to clarify, that if the state contracts with the private provider, that certain standards must be met under that contractual obligation, otherwise the state is...can be liable. [LR283]

BRUCE MASON: Right. If they fail... [LR283]

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SENATOR CORNETT: Okay, that's... [LR283]

BRUCE MASON: ...to supervise that the contract is being implemented appropriate, which means protecting the individuals that are the third-party beneficiaries,... [LR283]

SENATOR CORNETT: Uh-huh. [LR283]

BRUCE MASON: ...to wit, the individuals with the developmental disabilities. [LR283]

SENATOR CORNETT: One of the things that we have...I don't know about the rest of the committee, but have heard from a number of parents are that this brings back the issue of the parents' objections are not necessarily taken into account if the child needs to be moved or the adult needs to be moved to different services: We don't want our child moved; we like them where they're at. And I've heard it from both sides, from people at Beatrice and from Health and Human Services, that they don't feel that they can move people or...because of...or they're going to go ahead and move them even with the objections of the parents. Where does the individual come into play and their wishes? There was one group of people that I met while we were at Beatrice that had been in the same room together, three of them, for a number of years and the parents have requested that if they are outsourced that they are moved together. At what...who is taking into account, besides the parents and what the state wants, what the individual wants? These people have been together for the majority of their lives. Separating them would be very traumatic at this point. [LR283]

BRUCE MASON: Right. Right now, with all due respect, no one is taking that into account. Under the suggestions that I outlined that we initiated back in '72, a person would be appointed to represent that sole person, just like in juvenile court, just like in divorce cases. [LR283]

SENATOR CORNETT: A guardian ad litem? [LR283]

BRUCE MASON: And very much a guardian ad litem that the whole purpose, the whole focus of that representation is what's in this person's best interest. [LR283]

SENATOR CORNETT: Because some of these people are at a higher functioning IQ, whether they have behavioral disorders or not, they know what they want and that may not be what the state wants, that may not be what the community-based program wants, and it may not be what the parent wants. But there seems to be a component missing. [LR283]

BRUCE MASON: And that's why the procedure that I recommended that we did was successful. As individuals were placed into the community out of BSDC back in the

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seventies, under the provisions of the consent decree, there was a mechanism where guardians and parents could object, their wishes could be heard, and yet the interest of the individual could also be represented solely and that there was an opportunity to have a hearing on this. And it doesn't have to be a full-blown trial. [LR283]

SENATOR CORNETT: What happened to that? [LR283]

BRUCE MASON: Well,... [LR283]

SENATOR CORNETT: When did that go away? [LR283]

BRUCE MASON: The consent decree... [LR283]

SENATOR CORNETT: Expired? [LR283]

BRUCE MASON: ...only has a limited life. [LR283]

SENATOR CORNETT: Right, it expired. [LR283]

BRUCE MASON: It had about ten years, ten-year life, and it expired. [LR283]

SENATOR CORNETT: And the consent decree was not renewed and nothing... [LR283]

BRUCE MASON: Yeah, that's right. [LR283]

SENATOR CORNETT: And that process was let to lapse. [LR283]

BRUCE MASON: Yes. And in perhaps looking back, as historians are often...have the benefit of looking back, maybe there should have been efforts to continue that. Because apparently the same problems that existed that precipitated the filings exist in 2006 and '07 and '08 that suggest... [LR283]

SENATOR CORNETT: When did the decree lapse? [LR283]

BRUCE MASON: Oh, don't ask me hard questions, okay? I think it was '85, I want to say, about '85, 1985. [LR283]

SENATOR CORNETT: And it took approximately ten years to revert back to where we were in total, to where it's brought attention to itself. [LR283]

BRUCE MASON: Yeah. I don't think it...I think it probably reverted back more quickly but, you know, therein lies one of the problems of a facility, that sunshine oftentimes

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takes a longer time to get in because there's less access of individuals and people in that. And there were some CMS reports in the nineties that suggest that there were problems but not to the full extent that we have now documented in 2005, '06 and '07. [LR283]

SENATOR CORNETT: Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Thank you. This is just a follow-up to Senator Cornett's questions. So we had a mechanism to look out for the patient here, but are other states? Do they have some kind of mechanism like this? Because the guardians are, you know, if they...what you said, they can't make that decision, it's not their right to make a decision, are other states have a hearing process like this or are we unique? Are we the only state that's dealing with this? I can't imagine we are. [LR283]

BRUCE MASON: No, we're...Senator... [LR283]

SENATOR GAY: So what are the other states doing then? [LR283]

BRUCE MASON: In answer to your question, I think what's important to understand is that the guardian has a significant...their wishes should be very significant. They're responsible under the law. The law recognizes the guardian can choose certain medical treatments and certain courses of action to help or hinder the person; however, they should not be the sole factor. That's what I'm suggesting. They should be one factor in a myriad of other factors that are considered, all focused and try to narrow in on what's the needs for this individual here. And so that aspect, I wanted to clarify that; that I'm not saying they should be disregarded. I think that the law would say otherwise. Other states have done that and other states have implemented a similar-type hearing process. During the great bulk of the deinstitutionalization process in this country, which would have been in the mid-seventies to the early eighties, there were a significant number of hearings. Now facilities have generally, in recent time, attrited out, if you want to use a word like that, in the sense that the focus is not because there is not a placement in; populations are aging and facilities are in fact shutting their doors because of the simple fact that, you know, there isn't an increase in population. It's becoming cost-ineffective to have a massive facility unless you're going to use it for some other reason. So other states have utilized these hearings and these hearings work. They're just basic due process, you know, that comports with it. Health and Human Services has their own procedure, a similar due process hearing for someone that's denied services, that they contend they should either have more services or some services, that are on the waiting list, and these are administrative hearings. We're not...I am not a very bright individual. I can't...I steal ideas like, you know, I'm an engineer. I take this idea from this state and that. I don't have the ability to create innovation like

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that, but I do have the ability to go to other states and see what other states are doing, and that has been successful. [LR283]

SENATOR LATHROP: I do have some things I'd like to clarify with you, if I can. You told us that in 1972 you represented folks that lived at Beatrice... [LR283]

BRUCE MASON: Right. [LR283]

SENATOR LATHROP: ...in a class action against the state of Nebraska and that was in a lawsuit filed, wherein Jim Exon was the defendant. [LR283]

BRUCE MASON: One of the defendants, yes. [LR283]

SENATOR LATHROP: That resulted in a consent decree in 1975,... [LR283]

BRUCE MASON: Right. [LR283]

SENATOR LATHROP: ...which remained in force for at least ten years. [LR283]

BRUCE MASON: I believe, and don't hold my feet to the fire on ten years. It was about ten years, I believe. [LR283]

SENATOR LATHROP: At that point in time, the consent decree is dismissed and the terms of that were no longer controlling. [LR283]

BRUCE MASON: That's correct. [LR283]

SENATOR LATHROP: Your hearing process, the due process out of paragraph 22 that you described from the consent decree, is not the law in Nebraska, but that is your suggestion for a way out of what you described as a conundrum. [LR283]

BRUCE MASON: Yes, that is, Mr. Chairman. [LR283]

SENATOR LATHROP: Which is the competing interests between having integration, on the one hand, which is required by the ADA, and the wants of the patient or the resident, rather, and the...or the guardian of that resident. [LR283]

BRUCE MASON: That is correct. [LR283]

SENATOR LATHROP: Do you have a judgment, a legal judgment, not just an opinion but a legal judgment as to what weight the state must give the judgment or the opinion of a guardian or a parent or the patient or resident for that matter? Is there a weight where we say that's 90 percent of the consideration or it's 60 percent? Do reported

cases give us the weight to provide or to apply to the judgment of the guardian? [LR283]

BRUCE MASON: The standard that would be utilized in a county court proceeding as to that the action of the guardian was antithetical to the interests of the ward, and those are legal terms, would be an abuse of discretion; that it would be not based upon the best interests of the ward. That's the same standard, best interests of the ward, that juvenile court uses--the best interests of the juvenile. That is a flexible, case-specific, factual-specific standard. So I would say that clearly the law would require the actors, the state actors, to give deference to the guardian's wishes unless the guardian, in face of the professional's opinion, unequivocally said this person can benefit/thrive in a community setting and needs to be placed out. At that time, then in fact the guardian is no longer acting in the best interests of that individual and, therefore, placement into a community setting would be appropriate. [LR283]

SENATOR LATHROP: And I suspect this is going to be an important consideration as we move through this process so I want to ask a follow-up question, or make sure I understand it, and that would be we would, in the first instance, give deference to the judgment of the guardian unless we could establish by clear and convincing evidence that the guardian is abusing their discretion or judgment and not observing the best interests of the ward or the protected person. [LR283]

BRUCE MASON: Yes, except I would go into the intermediate step. How would we determine that that is an abuse of discretion would be that the professionals, both in the community and in the state facility, have assessed the individual and that the individual's wishes, if those wishes are able to be communicated, and he or she has represented that it's the considered judgment of the professionals that placement in this facility--Beatrice--is no longer appropriate for that individual and is not in his best interests. So it's a collective decision. [LR283]

SENATOR LATHROP: But as a lawyer, you recognize, you use the term abuse of discretion, also a legal phrase. Not...there's volumes of case law that are on what abuse of discretion means. That's a very difficult standard to overcome, would you agree? [LR283]

BRUCE MASON: I would agree and I think that's why it's imperative that the state give at least a certain deference to it, but not to surrender their obligation. Because ultimately, it's the state of Nebraska's obligation to make that decision, what's in the best interest, and legally, politically, morally, ethically, the wishes of a family member are important but they cannot be determinative only of the ultimate placement of that individual. Why? Because that individual's family member and that individual, they may be at odds with each other, and it's the state's duty, not to the family member but to that individual, and that ultimately is where that duty resides and reposes. [LR283]

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SENATOR LATHROP: But as we look at the process, the first thing we do is defer to them. If we don't like that, we'd have to have a hearing. At a hearing, we'd have to establish...someone wishing to move that resident to a community center would have to establish that the guardian is abusing their discretion, which is a pretty high legal standard, in order to prevail in making a move from a Beatrice-type facility to a community-type facility. [LR283]

BRUCE MASON: They're abusing that discretion if the evidence, by clear and convincing, shows that therapeutically it's in the best interest of the ward or the individual, the resident, to be placed in the community. Therein lies the abuse of discretion. If in the light of clear therapeutic evidence that in fact it's in Bill's best interest to be placed in the community, then that goes...that becomes a res ipsa loquitur that that's an abuse of discretion, because it's not...the guardian is no longer acting in the best interests of the ward. The best interests of the ward, with all the available scientific evidence, all the available professional evidence says this person can benefit there. [LR283]

SENATOR LATHROP: And you and I can imagine what that hearing would look like. It would be in front of an administrative law judge or some such person. But at that kind of a hearing, the state would present evidence that says this is why we think it would be therapeutically beneficial for this particular individual to go to the community, and the family is going to come in with somebody else that's going to say the guardian has a pretty good point here; this is a good place, there's reasons why we think it's a good place. And then a judge would have to decide whether or not, in the face of competing evidence, whether it's an abuse of discretion to...by the guardian to insist that the person remain at Beatrice. [LR283]

BRUCE MASON: Because it's not in the best interests of the individual. But we do that in all kinds of procedures so... [LR283]

SENATOR LATHROP: We do. [LR283]

BRUCE MASON: ...and we did it there. That's right. [LR283]

SENATOR LATHROP: I just wanted to clarify your testimony so that I understood it, because I suspect, looking down the road, that this is going to be a central issue. [LR283]

BRUCE MASON: There's no question in my mind, from 30 years of experience, plus years, that this is going to be...this is going to be the line in the sand. [LR283]

SENATOR LATHROP: I wanted to clarify a couple of other things. You used the phrase "our report," and "our" refers to the NAS? [LR283]

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BRUCE MASON: Yes, the...which... [LR283]

SENATOR LATHROP: And I'm not sure you made it clear your association with NAS and what NAS is, so maybe you could take a minute to do that. [LR283]

BRUCE MASON: Okay. First of all, I'm the litigation director. My job is to oversee the litigation. I've been doing that for a good number of years. And the Nebraska Advocacy Services is the Center for Disability Rights Law and Advocacy in Nebraska. What NAS is, is that there are a comparable entity in each of the 50 states. We're funded by the federal government to protect the rights of individuals with disabilities. I sit on the national legal committee for all of the P&As, protection and advocacy. We take a look at what's going on nationally; we decide to enter, as amicus curiae, friends of the court, in cases before the Supreme Court, Courts of Appeals, help other sister/brother PNAs throughout the states. There's one of us, there's an NAS, in every state and territory. [LR283]

SENATOR LATHROP: And that's by virtue of the federal government. [LR283]

BRUCE MASON: By virtue of the federal government. [LR283]

SENATOR LATHROP: And their responsibility is to make sure that those with developmental disabilities are properly cared for. [LR283]

BRUCE MASON: And those that have a mental illness. That's why we're actively...and I've litigated the conditions at the Lincoln Regional Center, the Hastings Regional Center where women were sexually abused while in the custody of the state of Nebraska and receive...and had it entered into a consent decree with...called the Caroline C. case and just recently settled those damage claims that you all had to approve for those women that were assaulted and sexually harassed while they were residents there. So we deal with that. We also deal with individuals in the community. I filed a wrongful death case against Beatrice that was settled. I filed a wrongful death case against a community program, for the death of an individual with a developmental disability, because of their negligence. So that's what we do. We attempt to seek full inclusion of individuals and to protect their civil rights and, at the same time, to ensure that their constitutional rights are being protected in whatever form we find those individuals to be, in whatever setting. [LR283]

SENATOR LATHROP: And just as an aside, the NAS does a lot of that by advocating, as opposed to just bringing lawsuits? [LR283]

BRUCE MASON: Yes, absolutely right. [LR283]

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SENATOR LATHROP: Okay. That whole bringing lawsuits makes people nervous sometimes. [LR283]

BRUCE MASON: Absolutely right. And, you know, we have a variety of other things that we do that are, as having practiced law for a long time, I'd say are much more important than litigation. You know, the courtroom is not always the best form in which to either reach resolution of the issues, and that's why this due process hearing becomes important. Because what happens is, is that having represented parents and guardians, when they make a...for 30-some years, when they make that difficult decision, years ago, to place a person in the situation such as BSDC, that's a decision made with great anguish and they...it's so difficult to express the feelings that they go through and then to hear that, well, we want to move him. I mean it just brings up all these emotions. That's why this due process hearing brings the parties together and there's a sense that somebody is finally listening. And we may not agree but let's try it. Let's work it out. Let's work this out a little bit and see what happens and we'll make sure that nothing is going to happen to your son or daughter, as best we humanly can. We can't guarantee everything. I mean, there's only two guarantees in life and that's death and taxes, so... [LR283]

SENATOR LATHROP: I have one other point. I do, I really appreciate you coming down here. It's been very helpful. You have given us the constitutional requirements the state has towards people who are under our care and whose liberty has been compromised with a placement in a facility. You've also expressed the importance of developing an integrated system and that testimony regarding an integrated system, the state would benefit from having somebody who evaluates the person and then we'd go pick the services we need. That's your opinion about what we could do better and how we could function better, as opposed to a legal requirement. [LR283]

BRUCE MASON: Absolutely right. [LR283]

SENATOR LATHROP: Okay. And that comes as...it's your judgment, after 35 years of being in this area. [LR283]

BRUCE MASON: Of seeing that it just doesn't work. [LR283]

SENATOR LATHROP: Okay. I just want to make sure we didn't... [LR283]

BRUCE MASON: And, as Senator Harms suggested, it's broken; it needs to be fixed. [LR283]

SENATOR LATHROP: Right. I think that's all I had, if anybody else has other questions. In seeing none, again, thank you for coming down, Bruce. I appreciate it. [LR283]

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BRUCE MASON: Okay. Thank you. [LR283]

SENATOR LATHROP: And I think we'll next hear from Jodi Fenner? Is it Fenner or Fenner? [LR283]

JODI FENNER: Fenner. [LR283]

SENATOR LATHROP: Fenner. All right. Like Mike? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: Family? [LR283]

JODI FENNER: No. [LR283]

SENATOR LATHROP: Okay. I had him for constitution a law up at Creighton, so...all right. [LR283]

JODI FENNER: (Exhibit) Well, good morning. Can you hear me? Good morning, Senator Lathrop and members of the committee. My name is Jodi Fenner, that's F-e-n-n-e-r. I'm the legal services administrator for Health and Human Services. I'm here today to provide additional overview of the laws pertaining to the state's obligations to serve individuals with developmental disabilities and to identify the source of our legal duties. I appreciate the opportunity to present this information to the committee, and I will try to be brief in areas that Mr. Mason has already covered. To begin with, the obligation of government to care for individuals in society who, for various reasons, are unable to care for themselves derives originally from our common law. This has been recognized as early as the King's Court in fifteenth century England. This obligation, referred to as parens patriae, as first articulated to cover individuals with mental retardation and other developmental disabilities in 1963 with the passage of the Maternal and Child Health and Mental Retardation Planning Amendments. These amendments provided grants to states for planning and comprehensive action to address this sensitive population. Later, in 1979, the United States Supreme Court, in Addington v. Texas, recognized that the state, in performing their voluntarily assumed mission of serving those with mental and developmental disabilities, should not impose unnecessary procedural obstacles for individuals needing those services. Then in 1993 the Supreme Court further recognized that, under the states' police powers, the state has, and I quote, a legitimate interest in providing care to its citizens who are unable to care for themselves, as well as authority under its police powers to protect the community from any dangerous individuals. And that was Heller v. Doe in 1993. Then again in 1999, the U.S. Supreme Court, in Olmstead, recognized that individuals with disabilities are inherently entitled to respect, dignity, self-determination, personal responsibility, the ability to pursue meaningful careers, privacy, and inclusion,

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integration, and full participation with society. Many have argued that Olmstead doesn't apply to this population of the developmentally disabled; however, the federal government has interpreted Olmstead to apply to all individuals with disabilities, including those with developmental disabilities. Olmstead requires the state, when it is providing care to individuals with developmental disabilities, to ensure that such care is provided in the least restrictive setting available, taking into account the resources available to the state, which also entails balancing those needs with others with disabilities, and the desires of the individuals being served. Olmstead does not take away an individual's right to choice, nor does it mandate the state provide an entitlement program to individuals with disabilities. It has been interpreted by the United States Department of Justice to require states to assess individuals to determine whether the lesser restrictive placements options are available and to provide informed alternatives to these individuals served. Olmstead is, in essence, a safeguard to ensure that states do not impede an individual's inherent civil rights. The Department of Justice's tool to enforce the Olmstead requirements is CRIPA, the Civil Rights of Institutionalized Persons Act. That's found at 42 U.S.C. 1997. Under CRIPA, the Department of Justice can impose civil and/or criminal penalties. The federal government imposes other obligations and restrictions on the states by attaching substantive requirements to their purse strings. Examples of these, and just a few examples, are Section 1905 of the Social Security Act that authorizes the Medicaid waiver funding program through joint federal and state developmental disabilities programs; and another one is 42 C.F.R. Sections 440 and 441, which cover home and community-based services. Generally, these funds and accompanying regulations are funneled through the CMS, the Center for Medicare and Medicaid Services. CMS has broad authority to interpret and apply their requirements on states. Their regulations generally relate to the standard of care and the requirements related to the mandatory active treatment and habilitative programs for individuals. Unlike the Department of Justice, who has prosecutorial enforcement powers, CMS essentially takes away your money. And finally, in 1971, in not necessarily date order, but the Developmental Disability Assistance and Bill of Rights Act created the DD Planning Council. This is a federally funded program that's administered by the department's Public Health Division and its Community Health and Planning Protection Unit, but it operates independent of the department. Just a couple of the things that it does: The Governor has 23 members that are appointed for three-year terms; essentially, the purpose historically is to reverse the bias against people with disabilities by focusing on these things--independence, productivity, integration, inclusion, and self-determination. The council has grant powers and other things, but it's important that it does operate completely independent of the departments. Those are...in general, that's the federal overview, and then moving on to the state overview, state law relating to individuals with developmental disabilities is derived from the Developmental Disability Service Act, and that's found in Nebraska statutes 83-1201 through 83-1227, and a copy of that is provided in the packets that we're providing to you today. And we also refer to this as the DDSA. This act defines a developmental disability as mental retardation or a severe, chronic disability other than

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mental retardation or mental illness which: (a) is attributable to a mental or physical impairment other than a mental or physical impairment caused solely by mental illness, because those people are treated through the behavioral health statutes; (b) is manifested before the age of 22 years; (c) is likely to continue indefinitely; and (d) results in various things--the case of a person under 3 years of age, at least one developmental delay; in the case of persons 3 years or older, substantial limitations on the following areas of major life activity, and there we have self-care, receptive and expressive language development and use, learning, mobility, self-direction, capacity for independent living, and economic sufficiency. The act, which was initially adopted in 1991, actually several years before the Olmstead decision, sets forth the Legislature's intent with regard to DD services, and I do want to walk through those because one of the things the act does, and we'll talk about this in a moment, is authorize and actually mandate Health and Human Services to adopt regulations. The Legislature's intent actually guides all of those regulations and it explains where departments...where we're coming from. Number one, all persons with developmental disabilities shall receive services and assistance which present opportunities to increase their independence, productivity and integration into the community; two, all persons with developmental disabilities shall have access to a full array of services appropriate for them as individuals; third, they shall have the right, to the maximum extent possible, to live, work and recreate with people who are not disabled; fourth, they shall, to the extent possible, be served in their communities and should only be served by specialized programs when their needs cannot be met through general services available to all persons, including those without disabilities; five, they shall have the right to receive age-appropriate services, consistent with their individual needs, potential and abilities; and six, they shall be afforded the same rights, dignity and respect as members of society who are not disabled; seven, they shall be assured a uniform system of compensation and training, and a full range of work site enhancements which attract and retain qualified employees. And eight and nine are priority systems: eight, the first priority of the state in responding to the needs of persons with developmental disabilities should be to ensure that all such persons have sufficient food, housing, clothing, medical care, protection from abuse or neglect, and protection from harm; and then nine, the second priority of the state in responding to the needs of persons with developmental disabilities should be to ensure that all such persons receive appropriate assessment of their needs, planning to meet their needs, information about services available to meet their needs, referral to services matched to their needs, coordination of services delivered, support sufficient to allow them to live with their natural families or independently, transportation to facilitate access to services, meaningful habilitation, education, training, employment, and recreation designed to enhance their skills, increase their independence, and improve their quality of life. In essence, the Legislature has set forth what we as an agency are to focus on, and has established a priority system for us to allocate the resources that you provide us. And that is exactly what we do through the regulatory process. In 1994 the Legislature recognized, in Section 83-1202.01, that there were not sufficient appropriations to fund developmental

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disability services for all those that were eligible. Thus, the Legislature amended the act to commit to pursuing full funding of community-based developmental disability programs in a reasonable time frame. As the eligible population has grown, this time frame has changed over time. We started with a goal of 1996, that was later amended to the year 2000, and now the statutory goal is 2010. Other significant impacts of the DDSA are, and all of these are in your packet: they create the position of the Developmental Disabilities Service Act director, that's 83-1209 and it sets forth the duties that the director is to undertake; the act creates local field offices throughout the state to assist with developmental disability needs; third, it assigns the responsibility for costs of services to individuals receiving services; fourth, it creates the Advisory Committee on Developmental Disabilities, which I'll talk about in a moment; it establishes requirements for the DD regions, such as the quality review team; sets forth requirements regarding contracts for special services, employment background check; and creates an administrative process to address complaints with regard to the department's implementation of the act. The DD Advisory Committee that I just referenced, that was created and it's comprised of a representative of a statewide advocacy organization for persons with DD, consumers, family members, and elected officials and interested citizens. Again, this is a committee appointed by the Governor, 16 members for three-year terms. Unlike the planning council, this is actually something internal to DHHS. Their membership and a summary of their ongoing activities can be found on the Department of Health and Human Services' Web site. The link is indicated in your...the packet that we're providing you. For the public, it's quite easy to go to. You just go to community-based services and you can follow the links and get there. Finally, in addition to the requirements set forth in the act, the DDSA, the Legislature directed the department to adopt rules and regulations to implement the act, and we have done so. These regulations have been promulgated in Titles 203 and 205 of the Nebraska Administrative Code. Those can be found on our Web site as well. They have also been included in your notebooks today. In addition to the DDSA, there are a handful of separate statutes that were adopted as early as 1885 to create the Beatrice State Development Center, define its purpose, and address collection of costs for BSDC services. Those statutes begin at 83-217, and you're also being provided with a copy of those today. In summary, what these statutes direct us to, and I'm quoting, the BSDC is to provide residential care and humane treatment for those persons with mental retardation who require residential care, shall study to improve their conditions, shall classify them, and shall furnish such training in industrial, mechanical, agricultural, and academic subjects as they may be capable of learning. Whenever the Department of Health and Human Services determines that continued residence in the Beatrice State Developmental Center is no longer necessary for the welfare, care, treatment, or training of such person, it shall have the authority to discharge or transfer such persons, as provided in 83-387, and 83-387, we've talked about the hearing process that was in the prior settlement agreement and it, in essence, is in statute. Discharge pursuant to 83-387 requires reasonable notice and any individual being discharged from a facility has the right to appeal their discharge. The only difference in the, as I understand, the

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terms of the settlement agreement and the statute is under the statute we don't provide attorneys for individuals who have appeals. They either represent themselves or their guardians hire a counsel for them. To date, we're not aware that there's ever been an involuntary discharge from BSDC, so this statute hasn't necessarily been utilized. We haven't had any appeals filed under this statute for discharge. In general, that's a summary of the state and federal laws that we apply at the Department of Health and Human Services, and I'm happy to answer any questions you have. [LR283]

SENATOR LATHROP: Very good. Thank you. Senator Cornett. [LR283]

SENATOR CORNETT: With the findings from the federal government, do you feel that...obviously, we haven't met our own standards or the federal government's standards currently with the current findings. Do you think that...well, trying to ask without being (laugh)... [LR283]

JODI FENNER: That's okay. [LR283]

SENATOR CORNETT: Do you think that BSDC is moving, or has over the past couple years...because I've been in the Legislature longer than a couple of the members of the committee but less time than Arnie. In the four years I've been here, we have heard over and over again BSDC is getting better, it is getting better, it is getting better, and then we find out last year that it's not getting better, it's getting worse. Do you feel that corrective...that the steps that had been being taken over the past few years were in the appropriate direction? And obviously this committee wouldn't be here if we didn't feel that changes need to be...needed to be made. Do you feel that corrective steps had been attempted, and was there any improvement made since the beginning? Because the reports that we have, if you look back over time, it actually looks like we've regressed since we started, rather than progressed. [LR283]

JODI FENNER: I think that depends on when you say when is the beginning. Is the beginning in the 1970s? Is it in '85, when the prior settlement lapsed? What we currently have, the three current reports--CMS, DOJ, and CMS...and Nebraska Advocacy, I'm sorry, I misspoke--those reports detail activities in 2006 and 2007. And if you look at CMS's first report, and not first actual report but their 2006 report, they indicated substantial improvement had been made and that's why they continued funding, so they gave the facility a second chance. And the reality is that even with all the resources that were thrown at the issues to be addressed, we didn't make the changes in the time manner in which they wanted them to be made. And I don't know that that would have been possible. Are we moving in the right direction? I can tell you we've talked at great length routinely with the Department of Justice. They do think that we're moving in the right direction. They seem to believe it's going to take longer than I think everybody...obviously, if this is a problem we could have solved a year ago then we should have done so. But in my discussions with the Department of Justice, I think we

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agree that we have to do the right thing and if that means moving a little slower than necessary than that's what we have to do. [LR283]

SENATOR CORNETT: What concerns me is losing the funding. [LR283]

JODI FENNER: Uh-huh. [LR283]

SENATOR CORNETT: How can we move forward if we don't have the funding? If the Department of Justice thinks we're moving forward and we're progressing towards achieving their goals, why are we facing losing our funding if they feel we are...have been improving? [LR283]

JODI FENNER: The Department of Justice doesn't deal with the funding issue. They deal with the civil and criminal penalties. [LR283]

SENATOR CORNETT: Correct. [LR283]

JODI FENNER: CMS deals with the funding issue. [LR283]

SENATOR CORNETT: How does CMS feel we're doing? [LR283]

JODI FENNER: Well, they just...the way CMS responds when you ask them, and I can say this because we did and when they came and did their outgoing report to the public, several members of the public asked, well, what do you think we need to do, and their response is, it's not our job to tell you what we think you need to do; here are the conditions of participation; we're telling you, you don't meet them. They really aren't receptive to open...haven't been receptive to open communication and giving specific suggestions. Department of Justice has been much more helpful in that manner. I don't know if that's the standard CMS practice. My understanding is they've been asked to come speak to you. We would really enjoy knowing specifically what they think we should address first. We are asking to have settlement negotiations with them, as we have done with the Department of Justice. We're hoping that those will be fruitful. I don't think it's in anybody's best interest that we lose funding, because the people who are harmed are the people who are entrusted to our care. And I firmly believe that CMS cares for those people as much as we do. It's a matter of we have to get through the technicalities and legalities of the process. Maintaining the funding is a priority for us, ranking right at the top, but we have to multitask and deal with all of the issues at once. [LR283]

SENATOR CORNETT: But we don't...do we currently have a plan in place on how to meet those steps for CMS if CMS won't communicate to us what their priorities are? [LR283]

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JODI FENNER: Well, we actually have an opportunity to. Well, they'll be in court. We've actually filed our initial documentation to the arbitrator. [LR283]

SENATOR CORNETT: Correct. (Inaudible) [LR283]

JODI FENNER: Now they have to come back and respond to that. They have indicated that they're willing to open up discussions now that we're in litigation. And from their perspective, maybe they didn't want to have those discussions earlier because they knew that we would be in litigation. I have no way of reading their mind. But it's our hope that we will do that. We do have a plan of correction that we developed and that we're implementing. That is what we shared with DOJ, and DOJ thinks that we're on the right track. Are there things that we could do better? Yes, and they've suggested a few things and we've implemented those into our plan. You know, it's our hope that we'll be able to CMS and the funding issue will be resolved, and we need to work through the next few years to get the facility to where it needs to be, not to get the facility to where it was in 2006, because I don't think anybody reading those prior reports can say that that's even where the facility should have been. We need to disregard what's happened in the past and look to the future and see what are these individuals entitled to. These are individuals who are entitled to dignity and respect and inherent constitutional and civil rights. This Legislature recognized that in the early nineties and I think that you're affirming that by doing what you're doing now. [LR283]

SENATOR CORNETT: One last question, and this has to do with something that you said at the very end of your discussion, that the guardians have the right of appeal... [LR283]

JODI FENNER: Yes. [LR283]

SENATOR CORNETT: ...if the state wishes to move them to a community-based... [LR283]

JODI FENNER: Uh-huh. [LR283]

SENATOR CORNETT: ...but that the patient does not, as an individual. I mean they...if, say for instance, you have someone in there that their parents have died. They don't have the resources to hire an attorney for themselves for the appeal process. [LR283]

JODI FENNER: They have the... [LR283]

SENATOR CORNETT: Who is their representative? [LR283]

JODI FENNER: Well, the federal government funds Nebraska Advocacy, who can act as their representative. [LR283]

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SENATOR CORNETT: But who...I mean a lot of these people wouldn't be able to contact Nebraska Advocacy themselves. [LR283]

JODI FENNER: Nebraska Advocacy is there... [LR283]

SENATOR CORNETT: Are they there? [LR283]

JODI FENNER: ...almost on a daily, weekly basis. [LR283]

SENATOR CORNETT: Okay. [LR283]

JODI FENNER: They have access to...I mean, if somebody was being discharged and complained, they have a representative who is there routinely that they could complain to. [LR283]

SENATOR CORNETT: A lot of the people that we saw wouldn't necessarily be able to complain. [LR283]

JODI FENNER: That's correct. [LR283]

SENATOR CORNETT: Do...and this goes back to the gentleman, I believe it was Mr. Mason, that was speaking earlier, do you feel that the patients need something equivalent to a guardian ad litem for themselves, to represent their interests? If their guardian is not alive or is not showing interest in them, who is going to represent the person? [LR283]

JODI FENNER: That is a very difficult question because, as you indicated, Senator Lathrop, a court appoints guardians. [LR283]

SENATOR CORNETT: Correct. [LR283]

JODI FENNER: It's not as if a family member just decides to be a guardian. They have to go to a judge and convince the guardian that they are going to act in the best interest of their loved one or in the interest of whoever it is who's been entrusted to their care, may not necessarily be a family member. If we were to believe that a guardian was not behaving appropriately, we absolutely would go to a court and ask that the court readdress that guardianship. So do we need a separate guardian ad litem in that process? Goodness, that's certainly a policy decision. It's something you could do but... [LR283]

SENATOR CORNETT: It's something that we did under the consent decree in the seventies, maybe not a guardian ad litem but somebody to represent? Is that what Mr.

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Mason said? [LR283]

JODI FENNER: And I don't know that detail. I, from my perspective, we have Nebraska Advocacy, who is federally funded...or federal mandated, state funded, so that they can represent the interests of individuals in these institutions. But also, again, when you say somebody who's nonverbal, if we have somebody in our care who isn't capable of making medical decisions themselves, we would ask the court to appoint a guardian for them, to find a guardian for them, and we do that routinely, not just in this program but in APS and in other issues. So I would hope we would never have someone who couldn't vocalize their objections, either themselves or through their guardian. [LR283]

SENATOR LATHROP: Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Jodi, when you speak about an institutional setting and a community-based setting... [LR283]

JODI FENNER: Yes. [LR283]

SENATOR STUTHMAN: ...for the patient, does the funding follow the patient? Is there different funding mechanisms in the different settings? [LR283]

JODI FENNER: Yes, there are different funding mechanisms through the different settings. We have community-based funding. We have funding for BSDC. In the last legislative session you did pass a bill that allowed us to...the funding from individuals with BSDC who we are moving into the community, for those people the funding follows the person. [LR283]

SENATOR STUTHMAN: Okay. Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Yeah, thanks. Jodi, I've heard, well, when Bruce Mason was speaking to us, he used the term "best possible extent," "generally accepted development." You used one in your slide,... [LR283]

JODI FENNER: We like those terms. [LR283]

SENATOR GAY: ..."maximum extent possible." I mean, to me, these are big, broad, vague terms. And I guess who do we look to when we're trying to narrow it down? And, I mean, that could be anybody in this room's opinion of what "maximum possible extent" is. But is CMS...where do we go find CMS regs or whatever it is to decide where these things are? Even if we had a hearing with an advocate and a guardian and all this stuff, what rules are we playing by to decide whether they're receiving the best care, the

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maximum possible extent, or how do we decide these things? Are they in a reg, federal regulations or...? [LR283]

JODI FENNER: No, the "maximum extent possible," that was language that the Legislature adopted and probably because it is hard to determine, as a Legislature, as you're probably seeing, struggling with this issue, how would you pass legislation that said you must do this in this case? You would have...whereas in your packet, your DD statutes are pretty thin. They would be like the Tax Code if you tried to articulate every requirement. You could do that, but I think that's why in 1991, when the act was passed, they used that understandably vague language. As courts have interpreted language like that, we are required to use reasonable judgment in interpreting that. And again, the word "reasonable," attorneys love that language and apparently senators do, too, because it's all throughout the statutes. That's a really tough one. [LR283]

SENATOR GAY: Well, how about this one: CMS doesn't use "reasonable." It's like you're going to do this, this, this and this, to me, from what I've seen. I've only been here a couple years, but it's very specific of what they'll pay for, what you got to follow, what you're going to do. So is that anywhere that I can go and have someone look it up for me and say, these are the 120 things we must follow? Or maybe it's 20, maybe it's 80, I don't know. Is that anywhere in the statute? [LR283]

JODI FENNER: Even then, what CMS does have is it has conditions of participation. And I'm sorry, Director Wyvill has more of that CMS outline that he'll be visiting with you this afternoon about, but it's not as open and shut as you mention either. It is in statute and they do have regulations that interpret their statutes and they can be found on the CMS Web site. But even with CMS, you know, one of the, for example, one of their guidelines will be to provide adequate protection and safety measures. We've asked them, what do you want us to do differently? Because as I understand it, and I've only been with the agency since November, we weren't doing things that much differently in 2006 than we were in 2005, 2004, 2000, 1995. I think as Bruce Mason indicated, we probably should have been doing things a lot better for a very long time. So I don't know. Does that mean that the surveyors are just being more sensitive? I don't know. But the conditions for participation are on the CMS Web site. They're not always as clear-cut as we would like them to be. I think a lot of it is common sense, are we providing care and safety and protecting the rights of individuals who are entrusted to our care, and clearly that's something we can do a better job at and it's something that we're working towards. [LR283]

SENATOR GAY: Thank you. [LR283]

SENATOR LATHROP: I do have some questions, and maybe some things that I'd like to clarify. You were here when Mr. Mason testified? [LR283]

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JODI FENNER: Yes. [LR283]

SENATOR LATHROP: Yes? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: Okay. And the substance of his testimony was this; that the Constitution, the United States Constitution, and in particular the Fourteenth Amendment, provides certain protections to people who are in custodial care. And would you agree with Mr. Mason that's the case? [LR283]

JODI FENNER: For individuals in custodial care, yes. [LR283]

SENATOR LATHROP: Right. And he suggested that the constitutional implications mandate that we...that the state has three different duties: first is to protect the safety; second is to provide habilitation; and then the third is to integrate as much as possible. Would you agree with his testimony that the constitutional requirements for someone in state custodial care give rise to those three duties? [LR283]

JODI FENNER: I think that's a combination of the Americans with Disabilities Act and the Constitution, yes. [LR283]

SENATOR LATHROP: The first two come from the Constitution and the third one, the integration, comes from the ADA. [LR283]

JODI FENNER: Yes, that's correct. [LR283]

SENATOR LATHROP: Okay. Now just as a matter of lawyer to lawyer, when we talk about federal law and, in particular, when we talk about a constitutional requirement, we can't legislate our way around that. [LR283]

JODI FENNER: Absolutely not. [LR283]

SENATOR LATHROP: True? So to the extent we see a second priority for the state of Nebraska is habilitation and that is a constitutional requirement, our statute doesn't control that situation; it is a constitutional requirement and we have a constitutional duty to habilitate people who are in our care. [LR283]

JODI FENNER: That's correct. [LR283]

SENATOR LATHROP: Would you agree with that? [LR283]

JODI FENNER: Yes. [LR283]

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SENATOR LATHROP: Okay. You talked a little bit about corrective steps leading to improvement. I did read the NAS report, or most of it, last night and it chronicles, sort of, our relationship with CMS since 2001. And you've seen that report, have you not? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: And as I read that report, it looks like CMS has come into the state of Nebraska and they've said these are the problems, and they have...we have these constitutional requirements and we...if they are, if I can use the term, they're the skeleton and the flesh comes to us through the CMS rules and regulations. Am I right? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: So what we have to do, what our standard of care is isn't exactly unknown or isn't exactly a mystery. It's actually found in the CMS code, true? [LR283]

JODI FENNER: Much of it is, yes. [LR283]

SENATOR LATHROP: Okay. So we know what we're supposed to do and they come in and they do evaluations. And as I read the history of our CMS evaluations and the state's response, it looks something like this. CMS comes in and says these are the problems. The state has responded by saying, we'll do this to fix it. CMS has come in and said, okay, what did you do? And we've said, well, we didn't even get everything done we said we'd do. And they say, you know, you're out of compliance. And then we say, well, we'll do this to get into compliance. And that's been the history since 2001--a series of evaluations, promises by the state followed by more evaluations where we admittedly haven't done what we promised we'd do and we remain out of compliance. [LR283]

JODI FENNER: That is correct. [LR283]

SENATOR LATHROP: And essentially what's happened to us, to us being the state of Nebraska, is that finally CMS said enough is enough. And we had in...I think it was December, we made our last promise and they came in since December and said, we're decertifying you because you've given us promises and you're not fixing the problem. Would that be a fair summary of our relationship with CMS since 2001? [LR283]

JODI FENNER: I think that's correct. [LR283]

SENATOR LATHROP: Okay. Mr. Mason also testified regarding...and I suggested, in

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questioning him, that it was going to become one of our central issues, and that is this idea of or the concept of to what extent does a guardian have control over whether someone remains at Beatrice versus goes into the community because that's what state personnel and doctors and so forth think ought to happen. And if I understood Mr. Mason, he suggested that there is...and he called it a conundrum, which is the tension between providing full integration and respecting the opinions and wants and the expressions from family and guardians. And you...that really is one of the conundrums in providing care and addressing placement for people with developmental disabilities. Would you agree with that? [LR283]

JODI FENNER: It can be. [LR283]

SENATOR LATHROP: And he has suggested that...and I want...I'm trying to get your opinion because... [LR283]

JODI FENNER: Okay. [LR283]

SENATOR LATHROP: ...I do, I think this is going to be central to much of what we do at Beatrice, and that is to get to the bottom of to what extent does a guardian have a say in the matter. And he has suggested that the ADA will provide deference to the guardian but that the guardian, while their opinion is entitled to substantial weight, it isn't control. Would you agree with that much or can I take you in little bits through that opinion? [LR283]

JODI FENNER: I would say it's not the sole controlling factor. [LR283]

SENATOR LATHROP: But it's entitled to substantial weight, or do you not agree with that? [LR283]

JODI FENNER: I do agree with that. [LR283]

SENATOR LATHROP: Okay. So, so far, the way we would sort that out is at one of these 387 hearings, an involuntary discharge hearing. What we would do is if a parent or a guardian objected, then we would have a hearing, and at that hearing the question would be whether the objection of the guardian to the involuntary discharge from Beatrice is an abuse of discretion. Do you think that that's how we would sort out, as lawyers, how we would sort out what weight we give the guardian's opinion? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: Okay. So you are in agreement with Mr. Mason in that respect. [LR283]

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JODI FENNER: Yes, I am. [LR283]

SENATOR LATHROP: And the last thing maybe, to follow up on a question Senator Cornett had, there is...Mr. Mason, in the consent decree, had provision in paragraphs 21 and 22 for the appointment of counsel for people at these administrative hearings. [LR283]

JODI FENNER: Uh-huh. [LR283]

SENATOR LATHROP: Our statute does not. Is that the case? [LR283]

JODI FENNER: That's correct. [LR283]

SENATOR LATHROP: And when Senator Cornett was talking to you about guardian ad litem, guardian ad litem are different than having a lawyer. [LR283]

JODI FENNER: Absolutely. [LR283]

SENATOR LATHROP: Anybody can serve as a guardian ad litem as long as they are suited, educated, and have the interests of the ward as their primary consideration. [LR283]

JODI FENNER: That's correct. I think there's actually some court training that goes into that process as well, but in essence that's correct. [LR283]

SENATOR LATHROP: But it doesn't make them qualified to serve as counsel. [LR283]

JODI FENNER: Absolutely not. [LR283]

SENATOR LATHROP: Okay. So how we sort that out is the person that's the guardian speaks for the ward, and if that person is...appears to be losing interest or appears to be not providing for the best interests of the person for whom they've been appointed then we can go back to the county court in whatever county that appointed them and have them remove. [LR283]

JODI FENNER: We can ask a judge to look at that. [LR283]

SENATOR LATHROP: And that's our remedy in that instance. [LR283]

JODI FENNER: It is. [LR283]

SENATOR LATHROP: Okay. I think that's all I have, unless that's provoked any other questions. Doesn't look like it. Thank you very much for your testimony. [LR283]

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JODI FENNER: Thank you. [LR283]

SENATOR LATHROP: And seeing that we're at 5 after 12:00, I think that will give us a good opportunity to take a break. [LR283]

SENATOR GAY: How are you going to do next few people coming up? Is there an order? [LR283]

SENATOR LATHROP: Yes. What we will do after we get back from lunch, just to kind of give you a preview, I think we'll start out with John Wyvill, who will give us kind of an overview of Health and Human Services, and then we will hear from Ron Stegemann, and we will hear from somebody with respect to community-based care. Am I right? [LR283]

JOHN WYVILL: And Lee, Lee Zlomke, Dr. Zlomke. [LR283]

SENATOR LATHROP: Okay. And by the end of the day we will also take up the population or the census of people who are receiving services from the state and those that are on the waiting list. Okay, why don't we get back together at 1:30. Thank you. [LR283]

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SENATOR LATHROP: ...the second half of our presentation, that's going to bring us to John Wyvill. Welcome. [LR283]

JOHN WYVILL: Thank you, Senator. Good afternoon, Senator Lathrop, and members of the Developmental Disabilities Special Investigative Committee. My name is John Wyvill, W-y-v-i-l-l, the director of Developmental Disability of the Division of the Nebraska Department of Health and Human Services. Most especially, I appreciate the Legislature taking on this issue. We all have the same goal of ensuring the best care possible for clients at BSDC as well as others with developmental disability. We are open to giving you any information that you need on this issue. On May 20 of this year, all of you toured the Beatrice State Developmental Center. We enjoyed having you at BSDC and hope you learned much from your visit. I would like to thank this committee for allowing us to present more information in the area of developmental disabilities. I will begin my testimony by providing you with an overview of Developmental Disability Services through a PowerPoint presentation which will be the 25,000-foot view, so to speak, which includes information on intermediate care facilities for persons with mental retardation and community-based services. More details on this overview relating to fiscal issues will be provided tomorrow morning. After this PowerPoint presentation, please, you can ask any questions you may have. After my presentation, Dr. Lee

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Zlomke, the acting director of psychology at BSDC, will provide information on the spectrum of individuals with DD, as well as their needs. Lee will then answer any questions you may have. After Lee testifies, Ron Stegemann, the chief executive officer of BSDC, will provide information on DD services available throughout the state, and Karen Kavanaugh, the administrator of DD community-based services, will then provide information on DD services available through community-based providers, a review of the numbers of persons receiving DD benefits through the state and/or community-based providers and the waiting list for persons awaiting services from the state for DD. Also for the benefit of all of you, we have compiled a booklet for our testimony today that's in here and also if you look at a tab on PowerPoint, you have our respective PowerPoint presentation as well as the supporting documentation. If you will wait a minute before I get started, so you can look and find that within that. There will be a couple of slides that I'll be going through very quickly because they've been covered by previous speakers and don't want to waste your time to get into the heart of the matter. First of all, for our mission statement for Developmental Disabilities: Through quality enhancement, support effective services that build on a person's strength and maximize independence. That is the mission statement for us. The next slide that will come up is the organizational chart of Developmental Disabilities which will be effective July 1. As you notice, we have recently announced the reorganization of Developmental Disabilities in which under one umbrella, under myself, the director, we have community-based services, Beatrice State Development services, and also planning and programming in the development section with Karen Kavanaugh as acting director for both. Previously, service coordination is currently right now under Children and Family Services. With the move of over 200 employees over on July 1, DD service coordination will be under the umbrella and you will see that the continuum of services will be under, for program and personnel, will be under one administrative umbrella. Who receives services from DD will be persons with mental retardation and/or developmental disabilities receive services. Eligibility is defined in Section 83-1205 of the Developmental Disability Services Act. Just as a point of clarification, this is an eligibility program; this is not an entitlement program. Services are provided by 33 public and private community-based providers at 70 certified programs at the Beatrice State Developmental Center and at the Bridges Program. The next three slides that I have discuss the Developmental Disabilities definitions that we have touched on with previous speakers so we will just go right through those. And based on the estimated number of people with developmental disabilities in the state of Nebraska, there are approximately 27,940 people have a developmental disability and that number is estimated based on a 2000 study showing a 1.5 percent (inaudible) percentage prevalence of developmental disability in the general population and a 2006 census estimate of over 1.7 million people in Nebraska. The number of people that we serve through DHHS is 4,512 in community-based services as of September 2007, and as of June 30, 2008, we have 276 people at BSDC. The question about how many people we serve also depends on, if you look at a chart, and at least with my eyes it may be a little too small for me to read here but up on the chart here, several clients that you will find

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during the testimony may receive different kinds of services. So if we look for the years of 2004, 2005, 2006 and 2007, you will see the breakdown of what kind of services a client or the family may need, which is day services, residential services, respite services or services at BSDC. We have other individuals that will be testifying later today that will be going into more detail to give you an idea. The next shot that we have is, Senator Lathrop had asked for the whole universe of DD funding, so to speak, in the state of Nebraska. And if you look at it in round numbers, we're looking at over \$273 million that we're talking about broken down by federal money, general revenue money, and cash money. And in the next slide we have, and this information will be...Sandy, from Legislative Fiscal Office, will be working with a much more detailed report tomorrow. But how we are funded, if you look at the pie chart, we have community-based DD waivers that take up 52 percent. We have medical services for DD clients, community-based services which is state funded only. We have BSDC, and then you have private ICF/MRs representing 7 percent. Then you have DD service coordination which is \$10 million and then you have DD administration and then that should give you an idea to get your hands around the number of dollars and the breakdown of funding. We receive federal funds through a variety of different ways, first of all, through the ICF/MRs. And then we have five waiver programs that will be discussed later. That will just give you an idea of the various waivers and the uses of them, for example. We have the comprehensive adult waiver program that is approved for 2,630, and as of the end of May we are using 2,369 of them. And you can see the breakdown of the other waiver program and then the administrative fund. Then we go to the heart of the questions that were brought up earlier about what is an ICF/MR. An intermediate care facility for people with mental retardation is primarily for the diagnosis, treatment or rehabilitation of the person with mental retardation or related condition. An ICF/MR provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision and integration of health or rehabilitative services to help individuals function at his or her greatest ability. They also provide health or rehabilitative services for individuals with mental retardation and they are surveyed by the Center for Medicaid and Medicaid Services. ICF/MRs provide active treatment or training on goals and objective to promote engagement of the individual doing daily activities. ICF/MRs promote independence and return persons to their home community. ICF/MRs provide residential care and day services environment and ICF/MRs provide a full range of services, including medical services and therapy. Center for Medicaid and...Medicare and Medicaid Services, Title XIX regulations of Medicaid, have the regulations governing the intermediate care facility for the mental retarded as part of the federal Social Security Act. So when you were hearing about the testimony earlier, you have the federal Constitution, then you have Congress that enacts laws, and then you have the regulations on a federal level that are promulgated pursuant to that grant of authority. All facilities that an ICF/MR must meet and include eight conditions of participation and 56 standards. Those eight conditions of participation are up on the PowerPoint presentation just for illustrative purposes of the areas that we must meet which is client protection, facility staffing, active treatment

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services, client behavior and facility practice, healthcare services, physical environment, dietetic services, and the governing body. The governing body consists of the director of Developmental Disabilities, the chief clinical officer, BSDC's CEO and medical director. And in closing, the last slide just gives you an idea of the number of ICF/MRs in the state of Nebraska. There are three others, three others, and Mosaic has one at Axtell, Beatrice, and the tri-city region, which is Grand Island, and those numbers there of 108 individuals, 127 individuals and 9 individuals give you an idea of the private ICF/MRs. Members of the committee, this concludes my general 25,000-foot view or overview of Developmental Disabilities that will hopefully help you in the weeks and months ahead. [LR283]

SENATOR LATHROP: Are there any questions for Mr. Wyvill? I do, if I can, John. If you don't mind, can you just give us, when we talk about...since we have toured Beatrice, I think we have an idea of what Beatrice is but when we talk about a community-based program, and I know you have somebody coming up to talk about them specifically but as long as we're on the big picture overview, tell me in a big picture way, first, what we do in the community-based programs and then, if I have a son or daughter that lives in my home and I want them to continue to live in my home, what are the array of services that are provided to day services? [LR283]

JOHN WYVILL: (Exhibit 1) Okay. Well, first of all, for community-based services, those services can be delivered in a variety of settings. They could be in a home, they could be in a group home, they could be that one of the providers may have a day program in which a client will be transported to a facility, like for example, DSN. Disability Services Network may have a vocational center where the client goes or what you've heard in the past, maybe called a sheltered workshop, where they'll go and they'll do work there. If you are a parent of an individual that's currently at home, what happens, you will be in contact with a person in service coordination, which is we have service coordinators throughout the state that will be working with the family and the guardian or the parent and see what services that they want. It could very simply be working with vocational rehabilitation, which is in the Department of Education, to see if there is any employment opportunities. It could be as simple as just coordinating respite care or other services to make sure that the family get relief. It just depends on the nature of the disability and nature of the services that they need. It just depends, Senator. [LR283]

SENATOR LATHROP: Okay. So we can, in terms of community-based care, it can range from going to a community-based provider and I'll use ENCOR as an example, staying in a group home which might be a residence in a neighborhood with four or five residents, developmentally disabled residents and they have staff from ENCOR and they kind of live in that environment and go to work during the day. [LR283]

JOHN WYVILL: Um-hum. [LR283]

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SENATOR LATHROP: That's an example of a community-based program. Is that a typical community-based program? [LR283]

JOHN WYVILL: From my experiences, yes. [LR283]

SENATOR LATHROP: Okay. [LR283]

JOHN WYVILL: The thing that we can do the best way that I think of for looking at it is, if you think about BSDC and you've heard others talk about an institution or facility, everything is provided there. So to use, from Arkansas, use the analogy of Hillary Clinton that use the book It Takes a Village to raise a child, everything is provided at the ICF/MR. The "village" is the ICF/MR. In a community-based there are several different things you have to go and it depends on where the residence is and what services they're trying to access. They have to go to the doctor. They have to go to get day services or they have to coordinate with somebody. At an ICF/MR they have to coordinate there. And that's one of the discussions that Mr. Mason was talking about. There you're taking...the advocates feel you're taking away choice because everything is provided to them there. [LR283]

SENATOR LATHROP: Okay. And you mentioned in the last slide ICF/MRs. I was thinking that it was only Beatrice and you mentioned Mosaic. [LR283]

JOHN WYVILL: There's three private ones. [LR283]

SENATOR LATHROP: The three private ones. Can you describe those? Are they homes or is that...these numbers look like they're institutions. [LR283]

JOHN WYVILL: To be perfectly honest, Senator, I have not been to visit those facilities so I could not tell you. [LR283]

SENATOR LATHROP: Okay. We'll save that question for somebody that follows. [LR283]

JOHN WYVILL: Okay. [LR283]

SENATOR LATHROP: Any other questions? Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Yeah, John, thanks for being here. How many day-care centers do we have in Nebraska, private, besides...does the state have some, day care, you know strictly day-care centers for...like, I know Madonna has one in Lincoln here. [LR283]

JOHN WYVILL: We don't have any day care at BSDC. I think a long time ago we did for

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our employees to use that for services. [LR283]

SENATOR WALLMAN: I also mean for clients, you know, that need watching during the day. Madonna has some, if you had a stroke or something, you know, they have...you can drop off your loved one there and have day-care services. Now do we pay for that as a state, you know? [LR283]

JOHN WYVILL: It depends on what services...it depends on whether they're respite services or day services that they have. It just depends on what the providers do. Miss Kavanaugh, who will be following up on me, can give you a more illustrative response to your question, Senator. [LR283]

SENATOR WALLMAN: Thank you, John. [LR283]

JOHN WYVILL: Okay. [LR283]

SENATOR LATHROP: Anyone else? Okay. Thanks, John. [LR283]

JOHN WYVILL: Thank you. [LR283]

DR. LEE ZLOMKE: Good afternoon, senators. My name is Dr. Lee Zlomke, Z-l-o-m-k-e, and I'm acting clinical director of psychological services at the Beatrice State Developmental Center, and that's a position I held from 1987 to 1997, so I'm back on a contract basis at this point. The address of that is in Beatrice, Nebraska, at 3000 Lincoln Boulevard. I have had 30 years of experience in providing services to persons with developmental disabilities both in residential facilities as well as community-based facilities and through private practice, both in Lincoln, as well...kind of an urban area for Nebraska and as well as outstate as far out as Ogallala and have seen some autistic individuals out there. So currently I am a clinical supervision consultant at Nebraska Mental Health Centers. I am CEO and kind of a jack-of-all clinical trades for Pediatric Psychology Associates, which is a private practice psychological services firm dealing with persons with developmental disabilities and mental health problems as well as children and families, and then also working under contract as the acting director at BSDC. I have a doctorate in psychology from University of Nebraska at Lincoln. I've been a certified and licensed psychologist for 20-some years and I'm a (inaudible) child forensic psychology as well. So I'm here to provide you with some information relative to the spectrum of individuals with developmental disabilities as well as providing some information about their needs that reach a medical necessity level of care and through community-based services and at the Beatrice Developmental Center. So to break those out, this is information that's been put together around April 3 so some things are slightly different with changes in needs and populations but we should be pretty close on these numbers. Some of the numbers are not exactly comparable between the community-based programs and BSDC, that some of those numbers are not collected

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in exactly the same way but I'll try to go through that and kind of show you where the major differences are. I'll try to talk to you about where the substantial differences are and how those might impact some of our treatment decisions. So the first slide we're talking about, the average age of persons in community-based services is 35.2 years, and at BSDC the average is 49 years, so obviously, quite a difference in that population characteristic, and you can see in later slides the BSDC numbers as well. As far as the level of mental retardation or developmental disability, cognitive disability that are seen, some, a few, in the community have no developmental disability or mental retardation. That's been deferred. There probably are problems there but it's difficult to determine exactly the level, is usually the case on those. Persons with mild deficits: 49.4 percent in the community, while at BSDC only 16 percent have mild disabilities. Moderate disabilities: 29 percent; at BSDC, 11 percent. Severe disabilities: 10.6 percent; and at BSDC, 12 percent. And profound disability: 6.4 percent, while at BSDC 59 percent of the population has profound developmental disability. And then unspecified: another 1.4 percent. Additional mobility and other support concerns are also as follows and this is coming from Centers for Medicare and Medicaid summary statistics. Autism: 261 individuals in the community or 6.5 percent; and BSDC has a similar number, fairly close. Cerebral palsy: 14 percent; BSDC's numbers again close. Epilepsy controlled: 14 percent; BSDC's number is close to that. Uncontrolled or difficult to control seizure disorders: 12 percent in the community; 39 percent at BSDC, a significantly different population there. Ability to walk: in the community is 91.5 percent and this is one of those areas where the numbers are difficult to compare so we'll talk about that a little bit when we get over to the BSDC side. As you can see, the vast majority of persons in the community are ambulatory and can walk, whereas at Beatrice, probably around 50 percent, so quite a bit of difference there. Limited to bed most of the day: only 6.6 percent of population in the communities; the population at BSDC would be significantly higher and we can talk about that a little bit later. Or ambulating with an assistive device: 17 percent in the community; 52 percent at BSDC, so quite a difference in the amount of orthopedic supports that are required. Hearing impairments, hard of hearing: 4.8 percent in the community; 26 percent at BSDC. Or completely deaf and hearing impaired: 1.9 percent; and similar number at BSDC. Visual impairments, some level of impairments: in the community at 8.7 percent, that would be noncorrected or unable to be successfully corrected, whereas 47 percent at BSDC, quite a difference. And then completely blind would be 4.3 percent in the community and a similar number at BSDC. And another statistic that is not in your file but we needed to talk about would be those persons with severe and persistent mental illness in addition to their developmental disabilities and that is 46.3 percent in community-based programs and 66 percent at BSDC, again, quite a significant and apparent difference there. And speech and language numbers are not collected in the community to a great extent nor is tube feeding or persons who require tube feeding accounted for in community-based programs. So just on a couple of those numbers that were a little bit difficult to understand, at BSDC 52 percent of the individuals have wheelchair, need a wheelchair for mobility, as opposed to ambulatory, 96 or 90-some percent in the community could

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ambulate. So there's quite a difference in the amount of ambulation support that's required. And speech and language: at BSDC 96.6 percent of the individuals there have identified communication skill deficits and that might be, they have good articulation, they can say the words or they have significant...they have ability to communicate simply but have difficulty in social language or complex language to meet their needs; 96.6 percent have speech and language needs that have been identified. Feeding tubes we talked a little bit about. In the community those are not tracked, but for BSDC, 19.6 percent of our individuals are fed through a gastric tube and take nothing by mouth, which requires quite a bit of medical intervention and specialized training of staff. So when we're considering this previously discussed demographics, we must be able to keep in mind that the acuity or severity of the resources that are required is also something to be careful with; that even if the numbers are equal, there may be quite a difference in how severe those problems are being presented or how much attention or clinical expertise is required to meet those needs and we want to be careful in making those comparisons to look at the severity of the problems. You have people who may, for example, may self-injure by mouthing on their hand, just sucking on their hand which can lead to skin breakdown and can lead to callouses and that can cause some medical problems, as opposed to people who are actually gouging at their eyes. It might be different in how you have to treat that but they would all be in the same category of self-injury so we want to be careful about that. So at that point, that's my prepared testimony at this time. I thank you for this opportunity. I'd be happy to answer questions, particularly if you have any about treatment needs of individuals that have dual diagnosis for mental health and development disabilities problems as that's kind of where I spend most of my time. [LR283]

SENATOR LATHROP: Very good. Thank you for your remarks. Are there any questions? Well, I do have a few that I'd like to visit with you about. You said that from '87 to '97 you were actually employed at Beatrice in the role of director of psych services? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: Is that right? And today you serve in an acting capacity on a contract? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: Can you tell us what you do now or what you used to do when you did this full-time? I appreciate your overview and the statistics that you've given me. Now I'd like to talk to you about your role as a psychologist at Beatrice. What do you do there? [LR283]

DR. LEE ZLOMKE: Well, previously I was director of clinical psychology and we had a

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department of 13 psychologists, all of whom started...many of whom started at the same time I did. We came in as a response to the Department of Justice settlement that had been testified to earlier. We came in to help upgrade the services in response to that and several of us have stayed for a long period of time after that. So I was that and then I also, later, towards the end of that, I was clinical director of all clinical services that were nonmedical. So I had a big role to play, I think, in all the active treatment services and therapies that went on that were not directed by the physicians. Now, I'm there about 16 hours a week, soon to be 8 hours a week, so obviously I have a much smaller footprint on how things can be organized and the clinical services that can be developed. I'm really now trying to focus more clearly on just plans, strategic plans and implementation and training of on-site staff to continue to make the improvements that are necessary to have minimally adequate behavioral health services there on campus. [LR283]

SENATOR LATHROP: "Minimally adequate" is the measure? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: Let me...we heard this morning that residents at Beatrice State Development Center have a constitutional right to habilitation. Are the psychological services that are provided under your direction part of that habilitation? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: So as...for people who are confined as folks are at Beatrice, they have a right, a constitutional right, to receive services that allow them to improve or to advance, given their limitations. Is that right? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: And your role in that process is to treat the psych or the psychiatric or the psychological, rather, part of that process. Is that right? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: And when you came in 1987, you said that was in response to the consent decree we heard discussed this morning. Is that right? [LR283]

DR. LEE ZLOMKE: I started in '78 and became director in '87,... [LR283]

SENATOR LATHROP: Okay. [LR283]

DR. LEE ZLOMKE: ...but in '78, that's when we came on. [LR283]

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SENATOR LATHROP: But it was in response to the fact that the habilitation wasn't happening. The consent decree is entered and now we're going to undertake to upgrade the services at Beatrice and they brought you on board for that purpose. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: At that time in '78, what was the population at Beatrice in round numbers? I won't hold you to it. [LR283]

DR. LEE ZLOMKE: Maybe a 1,000. [LR283]

SENATOR LATHROP: Okay. Awful lot of people. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: You became the director a few years after you arrived. How many psychologists did we have on staff at Beatrice when these efforts at habilitation to include psychological services was being done? [LR283]

DR. LEE ZLOMKE: Well, when I felt we were at our very best, when other facilities across the country came here to see how we did active treatment and psychological services, was in the early to and mid-nineties, in fact, and then at that point we had 13 psychologists on staff with...all of whom had around eight years or more of experience in behavioral health treatment with persons with developmental disabilities and we supervised approximately 60 subdoctoral people that helped in those areas. [LR283]

SENATOR LATHROP: You have mentioned something that I've heard said before and that is, at one point, and you said the early to mid-nineties, we were the gold standard in how to do this correctly. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: And that was at a time when you were the director of the nonmedical services? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: You just told us how many people worked and provided psych services at the psychologist level and at the level of trained staff. How many, when you came on board as an acting director, how many psychologists did we have working for us at Beatrice? [LR283]

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DR. LEE ZLOMKE: I'm not really sure at that time. I think it was probably about nine and now we're at seven and a half. [LR283]

SENATOR LATHROP: What do we need...what's the population there right now? [LR283]

DR. LEE ZLOMKE: Two hundred and eighty-ish. [LR283]

SENATOR LATHROP: Two hundred and eighty-ish. How many do we...is there a standard for how many we should have, given the patient population? [LR283]

DR. LEE ZLOMKE: The Department of Justice, I think, talks about in some of their letters, it's not really a standard, but they talk about a 25-to-1 ratio. And it's not real clear if they mean those are persons with direct psych needs or if that's your total population, some of whom may not need direct psychological intervention. [LR283]

SENATOR LATHROP: So how close, when you came on board as acting psych director, were we to the goal? [LR283]

DR. LEE ZLOMKE: Well, to be minimum, we were probably 30 percent short. [LR283]

SENATOR LATHROP: You know, you and I had a conversation the morning of the tour. Am I...I'm remembering that right? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: You and I talked before we started the tour. I thought you told me we didn't have any psychologists there? Am I thinking of a different discipline? [LR283]

DR. LEE ZLOMKE: We didn't have...we don't have a full-time psychiatrist. [LR283]

SENATOR LATHROP: Maybe that's it. You said something...I mean, if we look at the understaffed piece of Beatrice, how many full-time psychiatrists should we have? [LR283]

DR. LEE ZLOMKE: It's hard to say but we certainly...I think in the past we've had a little over half-time and did pretty well with him at that level, and we have fewer individuals now so I would think at the bare minimum it would be half-time, and I think the standards have been interpreted even more strictly lately so it may need to be a little bit more than that. [LR283]

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SENATOR LATHROP: All right. Are there professional disciplines that we should have at Beatrice that we don't have? And I know you and I had a conversation about some and maybe it was speech therapy, I'm not sure. Do you recall the conversation? [LR283]

DR. LEE ZLOMKE: Sure. Speech therapy, we're very short and I think we've had two resignations since then. [LR283]

SENATOR LATHROP: What's very short? [LR283]

DR. LEE ZLOMKE: I think they were less than half-staffed when they had the two. I think they have...it may be that we have none now or very shortly. [LR283]

SENATOR LATHROP: How many should we have? If we have none now, how many should we have at Beatrice? [LR283]

DR. LEE ZLOMKE: I don't have that. I don't have that number. [LR283]

SENATOR LATHROP: Is it two or ten or can you... [LR283]

DR. LEE ZLOMKE: Well, I think they've...I think... [LR283]

SENATOR LATHROP: I'm not asking you for the exact number, but I'm trying to get a sense of the staffing issues in the professions as we look at staffing issues at Beatrice. [LR283]

DR. LEE ZLOMKE: I think they've thrown around numbers like four to six, around in there somewhere. [LR283]

SENATOR LATHROP: Okay. So instead of four to six speech therapists, we have none. [LR283]

DR. LEE ZLOMKE: I think we're looking for some contract people. [LR283]

SENATOR LATHROP: That's been ongoing. I mean, we were there May 20, a month ago, and that was the situation and we haven't found any. [LR283]

DR. LEE ZLOMKE: Um-hum. I'm not up on that. [LR283]

SENATOR LATHROP: Are there any other professions, healthcare professional fields, for which we have similar understaffing? [LR283]

DR. LEE ZLOMKE: I think at the present time, for neurology, we have a part-time consultant. That is stretched very thin. I know our medical staff are very concerned

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about that, to get more neurology help, and that will be very difficult to find in the state. []
[LR283]

SENATOR LATHROP: And by that, you mean a neurologist? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: A medical doctor with a speciality in neurology? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: How many do we need in an institution that has people with these profound levels of disability? [LR283]

DR. LEE ZLOMKE: It's hard to say. I would think, when we were talking with the medical staff, I believe they were talking a third or to as much as a half-time consultant. [LR283]

SENATOR LATHROP: So half the time of one... [LR283]

DR. LEE ZLOMKE: Um-hum. Yes. [LR283]

SENATOR LATHROP: And how many...and do we have anybody doing that right now? [LR283]

DR. LEE ZLOMKE: He's on contract. I don't know how often he's down. [LR283]

SENATOR LATHROP: Are there any other medical specialties or care providers that were...I know we have and we can talk about the techs and the people that are the hands-on folks but how about the other specialists? [LR283]

DR. LEE ZLOMKE: It's a strong standard of care. It's not written anywhere but it's highly suspicious if you don't have certified behavior analysts on staff. They're master's degree, some can be a bachelor's degree, but it's specialized training for behavior analytic interventions and they're...they have to pass a nationally certified test and be trained under supervision. And I think there's only one in the whole state of Nebraska and we don't have him. But it's...DOJ will be very concerned if we don't find a few of those somewhere. [LR283]

SENATOR LATHROP: And they've expressed that. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: How many does DOJ think we should have? [LR283]

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DR. LEE ZLOMKE: I don't think they...I don't think they've put a number on that but a significant...so those would be part of our psychological staff if we were fully staffed and we'd say we'd need ten, you'd hope to have four or so of those would be behavior analysts. [LR283]

SENATOR LATHROP: Are there any other specialists or care providers that we should have and don't? [LR283]

DR. LEE ZLOMKE: I think those are the major ones I can think of. [LR283]

SENATOR LATHROP: I think that's all I have. Senator Adams. [LR283]

SENATOR ADAMS: While we're on numbers, I need to get something straight. Did I hear you say that when we reached the gold standard we had a census of about 1,000 clients? [LR283]

DR. LEE ZLOMKE: No, that's where we started. [LR283]

SENATOR ADAMS: That's where we started. And at that time we had 13 psychologists? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR ADAMS: And now were at about 280 with how many psychologists? [LR283]

DR. LEE ZLOMKE: Seven and a half. [LR283]

SENATOR ADAMS: And we're not at the gold standard. [LR283]

DR. LEE ZLOMKE: Well, when we were at the gold standard we probably had about 460 with the 10...with the 13 psychologists, so we downsized at lot during those early years. [LR283]

SENATOR ADAMS: All right. Let me ask you, if I may ask one other question about speech pathologist. Do you have an opinion as to why we cannot attract speech pathologists to fill these obvious positions? [LR283]

DR. LEE ZLOMKE: It's a very popular job to be trained in right now. School districts are recruiting them all over the state at a fairly high level of pay, so it's a combination of money and the job type as well. So schools, I think both of the people that we have leaving are going into schools so it's nine months. You know, you get some summertime off. And most folks are not trained coming out in the population like ours and so

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that's...it's stretching them a little bit and sometimes they're not really interested in doing that as your first job. So I think there's a combination of salary and the type, what the job really entails. [LR283]

SENATOR ADAMS: I don't mean to be discrediting what you're saying, but a year ago at this time we sat in a task force on special education and we were being told what a shortage we had in speech pathology because your world and the hospital world are robbing them all from education. [LR283]

DR. LEE ZLOMKE: Well, we'd like to rob a few more. (Laugh) [LR283]

SENATOR ADAMS: Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: You discussed the shortages in these professions and that's going on really statewide in all the medical field. Yours is very specific. It sounds like what your looking...can you go out around the country and recruit, I mean, like any other person would, to say, we need these a little worse than you, we'll pay up a little more? Or is it such a narrow field that we just can't find anybody? And why are we not...I guess what are the steps, if you can answer this, what are the steps we're taking to recruit? Because it's been now ongoing a year. We know our problem, we can't recruit them. Senator Adams just talked about the speech pathologists, that's a more growing field, I guess, but are there just so few we can't get them or? This always bothers me because I hear this when we're talking anywhere in the medical field--we just can't get these people. Why can we not get them here, in your view? And I know that's a big broad question, but in your view, why can we not fill these positions? [LR283]

DR. LEE ZLOMKE: Well, it has been difficult forever. It always has been. The way we got fully staffed a couple decades ago was we grew our own. The CEO at that time, together with the state government, let them have an education initiative where tuition was paid for, they got some released work time, we did a lot of support to help and we took a lot of people who were master's degree folks and turned and got them to go back and finish their doctorate and kept most of those people for ten or more years at the time. And that's how we got...that's the only way we got fully staffed even then. We started an internship program and were successful in keeping somewhere between a third and half of those individuals for the first 10 or 15 years. We just finished two new...we just finished two interns being trained at BSDC this month and the end of next month. Both are going back, making 70 percent more than we're able to offer here. And they are just not interested in staying, I think, even if we could get even with the money. They just want to be from where they came from, so we just weren't able to keep them. But that's why we try with that internship program to grow some people and get them interested in staying and we're hoping to be more successful with that. But we do

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advertise, we talk to other universities that turn out a quality of individuals that we would like to have. I work with...I supervise eight interns at one facility and two at BSDC and we talk with them about all the interns that they know and we've made contacts with them trying to say, we've got jobs here and you could come, and no, nobody even applied. So it's not like we're turning anybody down. [LR283]

SENATOR GAY: So a little follow-up then. [LR283]

SENATOR LATHROP: Sure. [LR283]

SENATOR GAY: So, I mean, that doesn't sound like a program that gets done overnight. That's a long-range planning issue. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR GAY: How long of range, I mean, to start something? [LR283]

DR. LEE ZLOMKE: It took us from '78 to '80 till about 1985 before we got to where we thought, in the consent decree, we were doing good care. So it's a seven, seven-year project under really good circumstances that I considered at that time. [LR283]

SENATOR GAY: Thank you. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: Just a quick question, and I may have heard you wrong. Did you say your hours were being reduced? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR CORNETT: Has the population decreased enough where...why are your hours being reduced? [LR283]

DR. LEE ZLOMKE: I just don't...I don't have that much time to give to it anymore. [LR283]

SENATOR CORNETT: Okay. It's your decision. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR CORNETT: Got it. All right. [LR283]

SENATOR LATHROP: Maybe the obvious question is, we must have needed a director

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and the best we could do is get an acting director to come in and work 16 hours a week, now soon to be 8 hours a week. Have we replaced you? [LR283]

DR. LEE ZLOMKE: Not that I know of. [LR283]

SENATOR LATHROP: Is that process under way? Are we advertising for that position and...? [LR283]

DR. LEE ZLOMKE: I'm sure that they're in talks with...because I think it will probably need to come through an agency of some kind, I would imagine. [LR283]

SENATOR LATHROP: A headhunting agency? [LR283]

DR. LEE ZLOMKE: Yes. I would think they're doing that. We've been talking about those things for quite a while. [LR283]

SENATOR LATHROP: All right. Senator Cornett. [LR283]

SENATOR CORNETT: You have a private practice now currently, correct? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR CORNETT: What are the considerations that you have decided that it's...I'm looking at, it is a financial issue, a time issue? What would be our obstacles at hiring someone for the position that you're currently holding? [LR283]

DR. LEE ZLOMKE: Well, for me, just that I've been there, done that, you know, I'm not...so and it is very...it's going to be high stress, it's going to lots of hours, it's going to be just plain a lot of work and a lot of change, a lot of turmoil, a lot of staff being pretty upset. I mean, it is a high stress time to make this many changes. And there's always the uncertainty of where is this going to go, where is it going to wind up? Are we going to be able to pass? So then you start to say, well, I've got a lot of practice going, do I give that all up and I get into this? If this doesn't work out, it's not so easy to get that all back. And I've kind of been into, for me personally, I've been into just doing a lot of different things, not one thing. So for me that's kind of where I would be looking at. I think, you know, to find someone that wants to be a director, if you've already been a director, to come here to do this under these kinds of conditions is a very difficult decision to make and if you haven't been, you're sort of unproven and you never know what you're really going to get when you do that. [LR283]

SENATOR CORNETT: And at 16 hours a week that you have been working up until now, would you consider that an adequate number of hours or should the state be looking for a full-time person for your position? [LR283]

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DR. LEE ZLOMKE: Oh, it definitely needs to be full-time. [LR283]

SENATOR CORNETT: Do you know if that's what they are doing? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR CORNETT: Okay. [LR283]

SENATOR LATHROP: Any other questions? Senator Adams. [LR283]

SENATOR ADAMS: I was just curious a moment ago when you said, why would someone want to come under these conditions? What are these conditions? [LR283]

DR. LEE ZLOMKE: The pressure from CMS and DOJ and, you know, the press of, oh, it's not a good facility, bad things are happening there, why can't people do better work, how could you be in charge of that and then look what it's doing. And so there's just a lot of pressure from people that there's a hundred things that need to be done. You need to continue to do really good care and get a lot better and justify what you did before and there's just many, many priorities, all of which are number one. [LR283]

SENATOR ADAMS: Thank you. [LR283]

SENATOR LATHROP: We didn't talk about this but this just occurred to me and that is the fact that we have psychological services. A lot of the people that are at Beatrice, perhaps by virtue of the very nature of the disability, it's not just low cognitive folks but there are people that have psych issues and you're working on behaviors and things like that and that's what your role is. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: Okay. Thank you. I think that's it. I appreciate your testimony today. [LR283]

DR. LEE ZLOMKE: Thank you. [LR283]

SENATOR LATHROP: Ron, did you fill out one of these sheets? [LR283]

RON STEGEMANN: I did and I happen to have it right here. [LR283]

SENATOR LATHROP: Great. You can just drop it in the box and we'll start with your name, and spell your last name for us, too, if you would. [LR283]

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RON STEGEMANN: I will. Good afternoon, I'm Ron Stegemann, S-t-e-g-e-m-a-n-n, chief executive officer of the Beatrice State Developmental Center, which I will refer to as BSDC throughout the rest of my time, that is located in Beatrice at 3000 Lincoln Boulevard. Prior to my appointment in December of 2007 as the CEO at BSDC, I was an employee for 18 years in various positions of increasing responsibility engaged mostly in the provision and monitoring of formal habilitation services. I've had the unique experience of working, at some point in time, with every home at BSDC and have experienced working with a wide range of intellectual and developmental disabilities and challenging behaviors. My purpose in being here today is to provide an overview of services provided by BSDC, the outreach and intensive treatment services, or OTS program, at BSDC and the Bridges Program located at the Hastings Regional Center, and to respond to any questions you might have to the best of my ability about those services or about the spectrum of services provided at BSDC. I would like to thank you also for visiting BSDC and seeing our facility firsthand. The Beatrice State Developmental Center was established in 1887. BSDC is a 24-hour intermediate care facility for persons with mental retardation, ICF/MR and related conditions. As such, BSDC, with approximately 750 employees, currently provide services 24 hours a day, seven days a week, to approximately 275 individuals who present needs throughout the entire spectrum of intellectual and developmental disabilities, including those with challenging behaviors. Along with providing residential services, BSDC provides medical and nursing, psychiatric, psychology, social work, dietetics, habilitation, dental, pharmacy, cosmetology, recreation, vocational, and religious services. Therapies available include occupational and physical therapy, recreation therapy, speech language therapy, behavioral therapy, and an audiologist. BSDC currently has 23 homes on campus and offers a full-sized gymnasium, zero-entry swimming pool, chapel of all faiths, senior center, social center, exercise room, and a cafe and snack shop for resident use. BSDC is the only ICF/MR that is administered and funded by the state of Nebraska. There are also three private ICF/MRs in Nebraska that serve approximately 244 people. The outreach treatment services program, or OTS program: The purpose of the outreach treatment program is to go into the community to help individuals and the community treatment team reduce problematic behaviors and improve quality of life. An OTS consultation involves a team from BSDC, such as a psychologist, human services treatment specialist, psychology intern, from the Beatrice State Developmental Center observing the individual in residential, vocational, community and/or educational settings. The OTS team also reviews the individual's file, examines behavioral data and interviews the individual and his or her family, front-line staff, teachers and other treatment team members. OTS consultations occur over a three-day period. During the first day, an initial meeting is conducted with the individual's community treatment team in order to update referral information and develop common goals for the OTS consultation. After the initial meeting, the OTS team begins observing the individual and interviewing members of the community treatment team. The OTS team typically observes the individual until he or she retires to bed or throughout the night if behavioral issues include the nighttime. On the second day, the OTS team begins observing the

individual when he or she awakens for the day. The OTS team continues to observe the individual and interview the community treatment team until midday, when the OTS team begins developing the recommendation package that will be presented at an exit meeting on the third day. The purpose of the OTS recommendation package is to assist the individual and the treatment team in reducing problematic behaviors and improving quality of life. As noted, the recommendation package is shared with the entire treatment team at an exit meeting on the third day of the consultation. A treatment team may or may not agree with the OTS recommendations. The treatment team will decide which, if any, of the OTS recommendations will be adopted. After the three-day OTS consultation, the OTS team will continue to consult with the individual's treatment team for at least 90 days in order to monitor progress and answer questions regarding recommendations. A follow-up trip can be requested and would include part of the OTS team returning to observe, collect information and provide a refinement of recommendations. The intensive treatment services program, or ITS: I will now share with you an overview of the intensive treatment services program. The ITS program is for individuals whose behavioral challenges require attention in a more secure environment. For this, BSDC offers a short-term, 90- to 120-day admission to ITS. The overall goal for an individual who enters this program is to return to their home community. It is a eight-bed, coed living environment on the BSDC grounds, and is licensed as an ICF/MR unit. Designed to meet the needs of those who have developmental disability and who also may be affected by mental illness, the ITS program utilizes a biopsychosocial approach to assessment, diagnosis, and behavior stabilization. Treatment encompasses a wide variety of modalities including behavior management, individual counseling, psychoeducational groups, recreational therapy, vocational therapy, and opportunities for individualized experiential learning. Recommendations for future supports are offered. Community staff training needs and environmental considerations are addressed and discharge plans are formulated in cooperation with service providers and/or family members. Follow-up services are available to facilitate successful transition from the treatment setting back to the community home and to provide continued support as recommendations are implemented following discharge. And lastly then, I will give you information on the Bridges Program. The guiding vision for the Bridges Program is that the provision of specialized supports will enable individuals with developmental disabilities, otherwise removed from society or restricted in some way, to have and experience opportunities for choice, empowerment, community involvement and to gain the skills necessary to live as responsibly and independently as possible. This program is a specialized developmental disabilities residential service designed to provide a structured therapeutic environment for persons with challenging behaviors that pose a significant risk to members of the community. These specialized services include treatment of the challenging behaviors, mental healthcare, habilitation services and the supports necessary for each person to realize their personal goals related to treatment and habilitation. The program is located on the grounds of the Hastings Regional Center where it has the capacity to serve up to 14 adult males. It is licensed as a Center for the

Developmentally Disabled, or CDD. And habilitative services are provided throughout each person's waking day, seven days a week, as well as providing overnight awake supervision. A program of the Division of Developmental Disabilities administered by the Beatrice State Developmental Center, BSDC chief executive officer has primary authority over and responsibility for the overall operation of the program. The Bridges Program manager has authority and responsibility of the overall on-site administration and management of the program. BSDC psychology services administrator provides the oversight and direction of the clinical treatment program. To be admitted to the Bridges Program, the person must have been diagnosed with mental retardation or a related condition and, as such, is eligible for services from the Department of Health and Human Services Developmental Disabilities System. These adults may need minimal to moderate support with activities of daily living but their behavior poses a moderate to severe and/or persistent threat to others. Intensive specialized treatment and a secure level of supervision are provided to prevent serious injury through aggressive acts or sexual behavior. The Bridges Program will be utilized when all other treatment options and less restrictive environments have failed or are unable to meet the identified needs of the individual. The goal of the Bridges Program is a reflection of its philosophy. That is, to help people gain the skills necessary to live as independently as possible through the provision of intensive, therapeutic treatment in a structured setting. To meet this goal, an array of service options is available and will be customized to each person's unique strengths and needs. Thank you. I'll be happy to take any questions you may have. [LR283]

SENATOR LATHROP: Senator Harms. [LR283]

SENATOR HARMS: Thank you. Thank you very much for coming. You know, I've listened carefully since we've come back from lunch about what you've all said. I guess what really bothers me is that what you're saying is really good but doesn't seem like it's working. When I go into the report, go into the findings, none of this stuff matches up. I mean your philosophy is good, but doesn't seem to be carried through, doesn't seem to be working, or we wouldn't be here having these discussions on these issues that were talking about now. So if that's true, whether the observation is correct or not, if you got all the power in the world, how would you fix this? [LR283]

RON STEGEMANN: If I had all the power in the world? [LR283]

SENATOR HARMS: Absolutely, and didn't have to answer to anybody, how would you fix this? [LR283]

RON STEGEMANN: Staffing, and that's not specifically the direct care staff. While that's been a large focus, I think Dr. Zlomke spoke about other staffing deficiencies that we have and he talked about in the area of psychology, it also exists in occupational therapy, physical therapy. We need a specialized group that contains speech language

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therapy, OT, occupational therapy, a nurse and others to be involved in dysphagia that work specifically on swallowing disorders. So it's a combination, it's a staffing issue but it's not one specific area where we're short of staff. It's not just psychology or just speech therapy. It is across the board. [LR283]

SENATOR HARMS: Okay. I'd like to go a step further then in regard to the staffing side of it. As I look at this, just reviewing it and after the tour that we had in Beatrice, it also looks like we had some really serious management issues so are you including staffing in that as part of the problem or just a shortage of staff? Because quite frankly, when I look at the issues you have in management, the simple fact is you have no communication, well, I shouldn't say...very little communication, it's not consistent. You don't have a computer system that functions appropriately, you don't have follow-up with staff in regard to medication and the issues and your reports are faulty. All those things add up to me, tells me that we have problems just in the management alone of this operation. Is that a correct observation? [LR283]

RON STEGEMANN: There have been issues associated with the management as well and those are issues that we are addressing currently. [LR283]

SENATOR HARMS: And so what are you doing with those issues? [LR283]

RON STEGEMANN: For the issues that you talked about with, for our computer system, Avatar has been brought in to BSDC but is hasn't been fully implemented, so we need... [LR283]

SENATOR HARMS: Just fixing...excuse me, sir. Just fixing the computer does not make it a manageable system. I mean, if the document is correct, which we looked at and read, which I took some time to read, you have a communication issue just within the organization. The left hand doesn't know what the right hand is doing. How are you going to bring it all together to make this functioning so that the people that we've placed in your trust is being appropriate. I said to the attorney that was here earlier that I think there's some real issues here of liability, I think there's some real issues here of accountability, and how are you going to resolve that? Because it all fits back to management. No matter what you do with your staffing, no matter what we do with the computer technology, it boils down to can we manage this system. And what are you going to do to fix that aspect because the rest of it will start to fall in place when you have strong management with the right background, the right degrees and the right educational services. [LR283]

RON STEGEMANN: First of all, for my clarification, which document are you referring to? [LR283]

SENATOR HARMS: Pardon me? [LR283]

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RON STEGEMANN: Which of the documents are you referring to? [LR283]

SENATOR HARMS: The report that we had when the feds were here. [LR283]

RON STEGEMANN: The CMS, the Department of Justice? [LR283]

SENATOR HARMS: The last one that you had. You know, you've got more than just one. It's the last one we had, the last when the feds were here that deals with Beatrice Development Center. It shows us the plan of all the issues that you've had, and the problems that you have; going to lose, what, \$28 million... [LR283]

RON STEGEMANN: Oh, so that would be the CMS report, okay. [LR283]

SENATOR HARMS: The whole thing is what I'm really driving at. That's the last one that I've looked at. It's the last one. That's what brought all of this. That's why we're all here at the table today, is that issue. And that's pretty clear and pretty distinct to me and they spell out pretty clearly what the management issues are here and so that's what I'm really driving at is, I mean, you can fix all these things but if you don't change the culture of the organization and I've been in plenty of operations where the culture had to be changed, not easy. And if you can't change that culture, you're not going to be successful here. [LR283]

RON STEGEMANN: Right. And there's no doubt that culture does need to change. One of the things we've been trying to do and Mr. Wyvill has been very helpful for me in my role is to make the facility more of a transparent organization so that it's not a small group of people in a room making decisions about what's going to happen at BSDC, so that we get out and we get information from the folks that live out there, the folks that work out there, and we make those decisions as open to everyone who wants to be involved as possible. We now have a leadership team that's representative of the entire campus. We've invited staff into those meetings, we've invited individuals into those meetings, so it's not so much a closed-door system as it had been for probably about the previous ten years from that. And we do have a lot of work that we need to do with the management issues. There's no doubt about that as well. However, as someone shared with me once, it takes about a hundred miles out in the middle of the ocean to stop a fully loaded tanker. When CMS hit BSDC in 2006, with all the issues that they brought forward in their first 431-page report, we were a tanker in the ocean and we were fully loaded, so it will take us time. And as Dr. Zlomke said just a little bit ago, it took them about seven years under ideal conditions to build a fully functional system. [LR283]

SENATOR HARMS: But, you know, we've had this issue since 1972. Then we fixed it for a short period of time and brought it back where we are, and maybe then worse than

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it was in '72. You've got the same issues. So my question really is, how much longer can we wait? And I'll leave it there, Mr. Chairman. [LR283]

SENATOR LATHROP: Questions? Additional questions? Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Ron, you talked about, you know, the staffing part of it. Do you feel that if there was more money allocated, increased wages would attract a lot more people for staffing? [LR283]

RON STEGEMANN: I can't really say whether or not that would bring more people into BSDC. That's one of the things that's been thrown around in the media. The staff at BSDC have indicated that they feel like they're not being compensated at a rate that's high enough where...and that very well may be true. But if you look at the level of pay that human services...employees in the human services field receive statewide, we've looked at Beatrice, we've looked at nonrelated positions within our area and it seems that the compensation is at a relatively high or higher-than level than all those rates of compensation. A big concern that I have was from the gentleman who sat in this chair before me, was that I...along with his having been there and done that, so to speak, and he was kind enough to come back to BSDC and really try to help us through that, is our ability to attract and keep qualified experienced professional staff in order to provide the services we need to provide. I'm not sure that were at an appropriate level for those folks, based on our having to bring some, for instance, pharmacy staff in and at at-will positions because their pay grade wasn't high enough to do it otherwise so. [LR283]

SENATOR STUTHMAN: Thank you for that. I have one other question. I don't know if I heard you right. How many employees do you have there? [LR283]

RON STEGEMANN: There's approximately 750 at the present time, I believe, and that's total. [LR283]

SENATOR STUTHMAN: 750 employees and 280 patients? [LR283]

RON STEGEMANN: I think, as of this morning, we're down to 272 and we do also, with that 750 employees, that's full-time employees, we have currently about 100 on-call staff who work directly with individuals also and that's not even a part-time level, it's an on-call type position so. [LR283]

SENATOR STUTHMAN: Okay. Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Thanks. Ron, we toured Beatrice but in Beatrice there's that Mosaic. What's the difference between what you're doing and what they're doing? [LR283]

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RON STEGEMANN: There isn't any other than the fact that they're smaller. [LR283]

SENATOR GAY: They're smaller. No difference whatsoever. Did they take the same level, do they provide the same level of care? [LR283]

RON STEGEMANN: Typically, and I'm more familiar with the Mosaic program in Beatrice certainly than in the other two locations but they don't. Because they're a private provider, they have the ability to pick and choose to a certain degree who they have in their program. So they don't have the severe behavioral challenges that we have at BSDC, and they wouldn't necessarily have the severe medical conditions that we see at BSDC. So they kind of fall in the middle somewhere, so to speak, in terms of developmental disabilities and ranges and some of those challenges that exist, and as a state organization we serve whoever comes, so. [LR283]

SENATOR GAY: So there's a big difference then between that, and then in Axtell is there another facility? [LR283]

RON STEGEMANN: There's one in Axtell and I believe there's a small one in Omaha, I believe. [LR283]

SENATOR GAY: So the same situation goes there, what you're telling us, they're picking a little easier clientele? [LR283]

RON STEGEMANN: I'm not going to say that but they do have the ability to kind of pick and choose who they're going to provide services for. [LR283]

SENATOR GAY: Okay. Well, I guess, what I was asking you though, what is the difference? And you're telling me the difference is the patients. You've got a lot more intensive care than they have, is what your saying. [LR283]

RON STEGEMANN: Right. They can terminate services; we don't. [LR283]

SENATOR GAY: And you don't have that ability whatsoever? [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR GAY: Okay. Thanks. [LR283]

SENATOR LATHROP: Senator Adams. [LR283]

SENATOR ADAMS: If I might, I'd like to go back on the line of questioning that Senator Harms had started--the culture. You're there, you've been there, so in your opinion,

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describe for me that culture that needs to change. [LR283]

RON STEGEMANN: One of the big pieces of the culture that needs to change, unfortunately, arose out of what Dr. Zlomke alluded to earlier, was that at one time the BSDC was the gold standard in terms of providing services certainly in the Midwest and probably nationally, and that was about the time I came on board as well, in 1989. Because we were considered to be one of the best programs in the nation, we became very protective of that image and so we quit going, once we had grown our folks to a certain degree, we quit going outside for new and innovative ideas and information. So we became a little bit...we excluded ourselves to a certain degree. Secluded ourselves from the rest of the DD world, so to speak, and said, well, we can do this on our own, we've done it before. And we have to change that. We need to get up to speed with the rest of developmental disabilities across the United States, and so that's part of what has to change. We have to get out of the idea that we know what we're doing, and that we don't need any assistance, because it's obvious that we do need to get new and innovative ideas and we need to upgrade our thinking with how we're going to be providing services. [LR283]

SENATOR ADAMS: Anything else? [LR283]

RON STEGEMANN: Another big piece of that that's different, of course, than when Dr. Zlomke was talking about periods of time ago, we do have a core group of wonderful and committed veteran direct care staff, as well as professional staff throughout the organization. Part of what's a little bit different now is some of the younger employees that we're getting on board. I remember attending a Sharing Our Best conference that we had at BSDC probably not more than five or six years ago or possibly a little later, and they told us, you will be getting employees in here that will not stay longer than a year or two and it isn't because they're bad people, it isn't because they're, you know, they shouldn't be in this field. It's just that that generation won't stick around very long. And so somehow we have to find a way to get people new into the organization to commit to the organization, to stay for long enough so that we can meet what's in the standards, which says that you need to have knowledgeable, trained staff that are providing services for the individual. If they're not staying longer than a year or so, it's very difficult to say that these are indeed knowledgeable and trained staff. So that's a big piece, I think, needs to change as well. And then, to kind of add to that, I would go back to what Mr. Mason said this morning in making BSDC. He talked about a one-system sort of issue. BSDC and the developmental disability system in Nebraska do need to come to a much better relationship in terms of statewide--how are we going to go about the business of providing services to people with developmental disabilities? And that's something, I think, that can be very exciting and that I'm looking forward to BSDC being a part of this, how do we bring all this together and really come up with an effective service delivery system that includes BSDC, that includes the private providers, mental health services, all of those issues, so. [LR283]

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SENATOR ADAMS: May I ask one more? [LR283]

SENATOR LATHROP: Certainly. [LR283]

SENATOR ADAMS: What do you think, in your opinion, has caused the riff, I use that word, that presently exists that needs to be unified or bridged? [LR283]

RON STEGEMANN: Between...in the system? [LR283]

SENATOR ADAMS: Exactly, the various... [LR283]

RON STEGEMANN: I don't know that there's necessarily...hasn't been a riff that's been created. It's kind of, within my experience and having been there about 20 years, it's always been kind of BSDC was down in Beatrice and doing their thing and the rest of the system kind of was out there doing its thing. So I think it's important now and I think the opportunity exists and I know Mr. Wyvill supports that becoming more of a one system where the right hand knows what the left hand is doing and there's much less confusion within that. And I see the future of BSDC as being...I talked about our intensive services unit, a short-term program where folks can come in who may need some stabilization, who may be struggling a little bit, and teams that we can send out for our OTS program to go out into the community and provide some expertise and assistance and stabilize in that environment. I see that program as possibly expanding at BSDC and becoming a resource statewide when people get into situations where they need additional support, and also a choice for families, for individuals in Nebraska, for those who have developmental disabilities, a choice of living, learning environments, if that's the one they're willing to make. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: To follow up on Senator Adams' question, that was where I'm going too. It just doesn't seem like anyone is working together. You have, you know, you guys doing your thing, then you've got community-based people doing their thing, and you know, it just seems like there's no correlation between the two. And I know with reorganization, that's what I've been looking for and I'm sure everyone here is. That's why we reorganized HHS and that takes effect July 1, so I don't have a big heartache with that but that's exactly what needs to be done, not just in this but in all your departments. And I know you play one portion of that and that's what the main focus is today. But hopefully, as we do a...Health and Human Services is doing a interim study on one-, five- and ten-year goals that we want prioritized, and Senator Stuthman will be working on that this summer and all of us will, but this is a perfect example of why we're trying to do that. I mean, you've got to work together. If we have a program, an internship program, that was the best and we let it pretty much disappear, then that's

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not going to happen overnight but we all need to be working together to get employees, do all these things we want fixed. And I know it's going to be tough and you can't...it's more of a statement, I guess, than a question, but it is frustrating when you don't see people working together, creating their own little island so. [LR283]

RON STEGEMANN: Well, just as a kind of a comment towards that, I think the reduction in census at BSDC and the number of folks that have gone into the community-based developmental disabilities provider system, as well as other services outside of BSDC, is evidence of a start that that is changing so...there's no way that we could have reduced our census and there's no way we can meet our goal without there being services out in the community and us working together and with service coordination in order to make that happen. So I think we have a start for that. [LR283]

SENATOR LATHROP: Any other questions? Oh, Senator Harms, sure. [LR283]

SENATOR HARMS: Have you given any thought to, you know, in the areas that you're really short, where you really need the help of working on an arrangement with the state and colleges to be able to give students, who are in that field that you're short, tuition waivers, free tuition, maybe their books and their fees, if they would come back and have to work at Beatrice for maybe five years, ten years, getting the brightest kids you have, students you have, and also in that whole process, having an internship where they'd come back and spend, you know, six months with you in some type of an internship to start to help us, you know, ease that stress and pressure? I know that they're young and inexperienced but at least they're going to be educated and they're wanting to learn and give that, because some...I know we've done that in rural America with the family physicians where they go to Chadron State College and some of these others and they complete their degree and they come back, have to spend so many years in that portion of rural America to pay it back or they have to pay it back in cash. Have you given that any thought to give us some help and some relief that might get these younger students, younger people turned on and into Beatrice? [LR283]

RON STEGEMANN: Actually, I reviewed the information specifically that you're talking about within the last couple weeks where it had the rural initiative. Now whether or not we could get something like that going at BSDC, based on my review, I didn't see that we would necessarily qualify for that. [LR283]

SENATOR HARMS: Well, we're going to change the law. [LR283]

RON STEGEMANN: Okay. [LR283]

SENATOR LATHROP: It's our prerogative. (Laughter) [LR283]

SENATOR HARMS: There's no problem, we've got so many people in here. (Laughter)

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[LR283]

RON STEGEMANN: Okay. [LR283]

SENATOR HARMS: I guess what I was just asking if you'd have any interest. If we have to massage that around to where you qualify, would you be interested? [LR283]

RON STEGEMANN: Absolutely. Absolutely. [LR283]

SENATOR HARMS: Thank you. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: I haven't read the contract that you have with your employees and I know that different state employees have different contracts and some have tuition reimbursement. Do you have anything like tuition reimbursement for any positions now in your contract? [LR283]

RON STEGEMANN: Yes, we do. And I don't know specifically who that would affect and that's all done through our human resources department. But we do have tuition reimbursement. [LR283]

SENATOR CORNETT: Do you know to what extent you already have that? Is it 50 percent? [LR283]

RON STEGEMANN: I believe it's 50 percent for educational needs, general needs, and up to 75 percent if it's specific to your job and your position to improve. [LR283]

SENATOR CORNETT: And is there a payback period like there is, I know, for legislative staff, that they have to work so many years after receiving that tuition reimbursement or pay back a percentage, depending on the number of years they work after? [LR283]

RON STEGEMANN: Yes, there is, but I can't tell you specifically what that agreement is. [LR283]

SENATOR CORNETT: Do you know if any number of employees are utilizing that currently? [LR283]

RON STEGEMANN: I can't tell you. I know that within the last year, they always send out information that money is available and then they tell us when it's gone, so I'm assuming folks are using it so. [LR283]

SENATOR CORNETT: Interesting question: Are you...how much are you budgeted for?

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Is there a cutoff point where then you don't authorize people even if you need... [LR283]

RON STEGEMANN: That I'm not sure about. We have to...we'd have to check with folks in our human resources who manage that piece of it for us. [LR283]

SENATOR CORNETT: Thank you. [LR283]

RON STEGEMANN: Kind as Dr. Zlomke alluded to earlier, they...there was a huge initiative at the time when he was at the master's level and went through and got his psychology degree and there were several of his colleagues that went through and did that. We basically paid for them to get doctorates. [LR283]

SENATOR CORNETT: And then they were required to work for so many years to return that? [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR CORNETT: Do you know if people are being denied tuition reimbursement currently? [LR283]

RON STEGEMANN: I can't tell you that. [LR283]

SENATOR LATHROP: Okay, I do have a few questions if everybody else is done. [LR283]

RON STEGEMANN: Yes, sir. [LR283]

SENATOR LATHROP: You talked about, going back to the staffing issue, there are...and we're going to have a day probably in August where we'll talk about staffing in more detail but I do want to ask you this and it's kind of a staffing/money question. And that is, you talked about there is a chronic shortage of direct care staff, which would be sort of the tech level people that are involved in the face-to-face care of the residents, but also that you had shortages in occupational therapy, physical therapy, speech therapy and nurses who can work with swallowing disorders, among other things. [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR LATHROP: Apparently you have a problem with finding a director for psychological services and a neurologist to provide staffing at Beatrice. Are there other areas or does that cover it? [LR283]

RON STEGEMANN: There are other areas. I'm currently in the process of working on

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getting four administrative level staff in, in the areas of active treatment, residential services, quality improvement, and then someone to run our investigations. [LR283]

SENATOR LATHROP: Okay. [LR283]

RON STEGEMANN: And we're in negotiations for a contract to get that completed. [LR283]

SENATOR LATHROP: These staffing shortages have been the subject of CMS reports and they are not new to you, is that true? [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: And the fact that you have staffing shortages, is it because we, as a state, have not allocated the money for you to hire these positions or you just haven't been able to fill them? [LR283]

RON STEGEMANN: I'm not sure which it is or if it's a combination of the two. [LR283]

SENATOR LATHROP: A little bit ago there was...and I think this was in response to some questions about the difference between the Beatrice and a Mosaic, for example, and the point you made was is that Mosaic or some of these community-based providers who want to develop their populations in their programs can essentially come to Beatrice and read through people's files, do an evaluation and an assessment, and then decide if they want the person or a particular person at Beatrice or not. [LR283]

RON STEGEMANN: No, we wouldn't let them come and do that. [LR283]

SENATOR LATHROP: Isn't there an evaluation process if you propose to have somebody move from Beatrice to a community-based program, that community-based program can do an assessment to see if they're willing to take that person? [LR283]

RON STEGEMANN: If it was on the person's initiative and/or their guardian, then we would allow them to look through that information, yes. [LR283]

SENATOR LATHROP: I'm not suggesting there's anything wrong with that but the net result is that you end up with the population with the most needs. Would that be a fair way to put it? [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: Because when somebody comes, they may say, well, I can't take somebody that has cognitive difficulties and cerebral palsy and behavioral

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difficulties, I can't take those people into my program, and so that person remains at Beatrice. [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: And what has happened by virtue of that process happening over and over and over is that the Beatrice Development Center has, generally speaking, the higher needs population than do community-based programs. [LR283]

RON STEGEMANN: Generally speaking, yes. [LR283]

SENATOR LATHROP: We can agree that that's generally true. [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: I want to ask you about the criteria and I don't know if the criteria for people to remain at Beatrice is a function of that process, which is to say nobody in the community has picked them up, or if they are there because of particular needs that they have. I want to give you...remind you that when you and I did a tour there were...we were going through one of the houses or one of the buildings and you suggested that some of these people have behaviors that can be misunderstood out in public. [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR LATHROP: All right. They might approach somebody and somebody in public might misunderstand the nature of their attempt to approach them, just as an example. [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR LATHROP: So what's the criteria for retaining people at Beatrice? Is it because we can't get them into a community? Or do we have a criteria for retaining them because of their behaviors, because of their needs? [LR283]

RON STEGEMANN: I don't believe there's a criteria for staying at BSDC, if there is a provider out there who can meet an individual's needs that can serve them in the community. So there's no criteria then to stay. [LR283]

SENATOR LATHROP: No one could argue with that statement. The question is, in reality, are there people that can...providers that can meet those needs or does the fact that we have this population at Beatrice with significant needs suggest that Beatrice is the only place where those needs are being met in the continuum of care providers?

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[LR283]

RON STEGEMANN: Presently, yes. Yes. [LR283]

SENATOR LATHROP: Now, that being true, can we talk just for a second about what that means. Are these folks who are at risk to harm themselves or somebody else? Is that part of the Beatrice population? [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: And they are the folks that, for whatever reason, don't seem to be placed in the community. [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR LATHROP: And there are people who have behaviors that can be misunderstood and, as a consequence, they could be at risk or someone in the community could be at risk if they were in a community-based setting. [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: So do I understand then that at some level we need a Beatrice for these folks who are safety risks in the community? [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: Defining what the criteria is or what that population should be may be for another day, but at least we can agree that we need Beatrice for ITS, we need it for some of the other services, and we need it for those people who are at risk, whose safety is at risk if they're in the community. [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: All right. That, I think, is all I had and I don't know if that's prompted any other questions. Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Yes, hi, Ron. [LR283]

RON STEGEMANN: How you doing? [LR283]

SENATOR WALLMAN: Is there a waiting list of clientele that wants to be admitted to BSDC as of right now? [LR283]

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RON STEGEMANN: It is my understanding, there is no waiting list for BSDC... [LR283]

SENATOR WALLMAN: No waiting list. [LR283]

RON STEGEMANN: ...with the exception of, they do maintain a list of individuals for our ITS program so that they can be prioritized in the event that they would need those services. [LR283]

SENATOR WALLMAN: Okay. Thank you. [LR283]

SENATOR LATHROP: I think that's all we need. [LR283]

RON STEGEMANN: Thank you. [LR283]

SENATOR LATHROP: Thank you very much for your testimony. I think Miss Kavanaugh is up next. Good afternoon. [LR283]

KAREN KAVANAUGH: Good afternoon, Senator Lathrop and members of the committee. My name is Karen Kavanaugh, K-a-v-a-n-a-u-g-h... [LR283]

SENATOR LATHROP: Miss Kavanaugh, I'm going to...just before we even start, let's have you move that mike a little bit closer and speak up just a little bit louder so everybody in the back can hear you. You have a soft voice and we want to make sure we get a good record and that everybody has a chance to hear what you have to say. [LR283]

KAREN KAVANAUGH: Okay. I am acting administrator of the community-based services and planning section of the Division of Developmental Disabilities. My purpose in being here today is to provide additional information about the developmental disabilities services available through community-based providers and the numbers of persons currently receiving those services. On the community-based side, the division provides services for 4,116 persons as of June 6, 2008. These services include day or vocational services, residential and respite services. Within the Division of Children and Family Services, DD service coordination provides services to just over 4,500 persons, which would include the 4,116 persons served by the Division of Developmental Disabilities. The service coordinators will move from Children and Family Services to the Division of Developmental Disabilities on July 1, 2008. A fundamental premise of DD service provision is that we do not attempt to recreate services that are available to every citizen of a community. Instead, we support people to fully integrate into their community and access community resources. What the Division of DD does do is to support development of specialized services. This means that funding comes through the Developmental Disabilities Division and goes mainly to specialized community-based service providers with whom we contract to provide services specially

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designed to meet the needs of persons with developmental disabilities. Habilitation is the difference between providing care and specialized service delivery. Day and residential services are expected to include habilitation training and supports designed by the person's team to help the individual become as independent as possible. Specialized respite is not intended to be habilitative, because it is generally short-term relief for the usual unpaid caregiver, who is generally a family member. However, staff who provide the service must have an awareness of the person's strengths and needs in order to meet their needs. Community supports waiver services are services which are not provided by specialized providers, but it is more than simply care, as you will hear later. Community supports waiver services are designed to give the person and family a choice that includes no requirement of habilitation and allows more flexibility to meet the needs of the person. There are currently approximately 3,500 people receiving day or vocational services. These services are delivered during weekdays, during the time that people generally work or are in school. For the rest of the day and weekend, residential services are available. There are currently just over 3,000 persons receiving these services. Day and residential services are further designated as either assisted or supported services. More often than not, assisted services are provided in group settings where staff are providing service to more than one individual on an ongoing basis throughout the time they are in the service, while supported services are generally provided on a face-to-face basis for brief, discrete periods of time. Assisted residential services are delivered to individuals who require the ongoing presence of provider staff to meet their residential needs. Assisted residential services may take place in a group home setting or an apartment where two or three individuals live with staff present whenever any of them are at home, or in an extended family home where an individual lives with a family who is paid by the specialized community-based provider to provide habilitative services. In assisted residential services, one can expect staff to be present overnight and during any daytime hours when individuals are at home. Supported residential services, on the other hand, are delivered to individuals who require the presence of staff only intermittently to meet their residential needs. This may be because the individual is more independent and can live in an apartment or house without supervision most of the time or because there are natural supports in place, so that 24-hour provider supervision is not needed, such as when an individual lives in the family home and provider staff are needed only a few hours a day or week; i.e., in-home supports. In either type of residential service, the community-based provider is expected to provide habilitative training and supports designed to meet individuals' needs. Typical training programs would teach skills such as hygiene, socialization, communication, and independent living skills such as budgeting and shopping, cooking, housekeeping, and laundry. Behavior management programs may be a part of an individual's residential services. Provider staff may also need to support individuals in either setting, with transportation and duties such as writing checks, handling mail, medication administration, and going to the doctor. The decision as to which type of residential service the person usually gets comes down to the person's need for supervision and supports, as well as personal choice. Similarly, assisted day services are for individuals

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who require the ongoing presence of provider staff to meet their needs during normal work hours. Assisted day services may take place in a shelter workshop, volunteering at community settings, or during work crew activities such as working on a mowing crew or a janitorial crew in local businesses. Also included are work stations in industry, where provider staff may operate a work crew in a factory setting. In assisted day settings, one can expect staff to be present during any hours when individuals are getting day services, generally weekdays. However, this service can be adjusted for work crews that work evenings or weekends. Supported day services are for individuals who require the presence of staff only intermittently to meet their needs during work hours. Supported day services are generally provided face to face and may involve job coaching or individualized support to apply for jobs, work as a volunteer, or work on specific work-related skills. Again, in either type of day service, the community-based provider is expected to provide habilitative training and supports designed to meet individual needs. Specialized respite services are also available. These are services where families can receive trained staffing support to give them a short break from caring for their own child. There are currently 480 families receiving this service. Respite services include supervision and activities organized to meet the physical or psychological needs of the individual, which may include intervening with inappropriate behaviors. The community supports program is the most recent addition to the Division of DD-funded services, having been approved as a Medicaid waiver in August of 2006. The community supports program is a program where persons, with the aid of family and friends, hire and fire their own personal provider to meet their needs. This program allows persons to self-direct their services, thus increasing their control and the accountability of their provider in meeting their needs. People accessing this service assign or agree to allow DHHS staff to contract with independent, nonspecialized providers, authorize services, and pay providers for the services provided. Currently, there are approximately 60 persons in the community supports program. In some respects the community supports program shares some similarities with supported services. There is an exception that the individual will not generally need ongoing supervision from a provider but will get face-to-face services to assist with activities of his or her choice. Typically this funding pays for assistance with personal hygiene and grooming, housekeeping, accessing community resources, activities and events, obtaining and maintaining employment, developing self-determination and self-advocacy skills, or maintaining a personal and social network of persons who can provide supports. Unlike other services, the community supports program can pay for personal emergency response systems, assistive technology and supports, home modifications, and vehicle modifications. Currently, funding is limited to the eligible person's authorized amount, or \$20,000 per year, whichever is less. In this final part of my testimony, I will discuss the number of persons who have requested services but are not receiving them. There are many ways of discussing waiting lists, and I will try to provide sufficient explanation, to avoid confusion about the numbers. When asked about a waiting list, we can provide either the total number of persons who are waiting for services, including those who are past their date of needs, and those who are

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requesting services in the future. This can provide a relatively inaccurate picture of the number of persons who want services now and in the future, as the request for services extends 20 years into the future, and there may be additional requests after today that will be for services before the year 2028. Therefore, the figures shown here will be for persons who are truly waiting for services; that is, those who, had funding been available, stated that they wanted to begin services prior to June 1 of this year. There are a total of 1,772 persons who fit into this category. Of that number of persons, 738 are currently receiving some services and are requesting additional services. The remaining 1,034 persons are not currently receiving any hard services from the division, though they may be receiving service coordination. The breakdown of services requested is as follows. Note that the numbers will add up to over 1,772, as some persons are waiting for more than one service. There are 422 requests for day services, 1,559 requests for residential services, and 316 requests for respite. There is an obvious disparity in the number of requests for residential services, especially relative to the number of requests for day services. This occurs, as the Legislature has funded day services for graduates from Nebraska high schools for the past 15 years. Thus, most persons have been able to have funding to meet their day service requests, which has significantly reduced the number of persons waiting for day services. This is further illustrated when we look at the waiting list requests for persons who currently are in services. Of those 738 persons, there are only 46 requests for day services, 57 requests for respite services, but 691 requests for residential services. Thank you. I would be happy to answer any questions that you may have. [LR283]

SENATOR LATHROP: Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Karen, just on your last comments, as far as the group of people that are not getting any service,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR STUTHMAN: ...what are they doing? Are they just staying at home? Are they just not...don't have the, you know, the ability or they are not receiving service? And most of them are day service, where someone needs to just be there for the day, or something for them to do. What are they doing? [LR283]

KAREN KAVANAUGH: It depends on the person and the family. Some of those children may be very young children who are still just living in the family home, but their families have thought ahead and are requesting services far into the future. And then there are another group of individuals who would be living their lives in their communities, with natural supports. [LR283]

SENATOR STUTHMAN: One other question that I have, Karen, is do...the people that are receiving community services, do they come from communities or do they come

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from an institution? Do you see many come from an institution to the community service? [LR283]

KAREN KAVANAUGH: I think the data would reflect that there has not been a great number of people coming from the institution in recent years; however, of course, this year there's been a significant impetus to have people move from the institution into the community. Many of those early placements were going to nursing facilities in communities, but we are also seeing people that are coming out into community-based services that are authorized for specialized community-based services. [LR283]

SENATOR STUTHMAN: Thank you, Karen. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: Is there a waiting list for 24-hour care? People that...like parents that know they're no longer able to care for their children, that would not be eligible to live on their own? [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: So we have a waiting list currently for people that need 24-hour care. [LR283]

KAREN KAVANAUGH: If you look at 24-hour care, I guess I'd look at it from the perspective of, that means that they're looking for day services and residential services. [LR283]

SENATOR CORNETT: Yes, not something...do we have anybody waiting--and I know this was asked earlier,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: ...for a place like Beatrice, where they need 24-hour care in the same facility? [LR283]

KAREN KAVANAUGH: In an institutional facility? [LR283]

SENATOR CORNETT: Yes. [LR283]

KAREN KAVANAUGH: The only waiting list is again, as Ron had stated, the people who are waiting for the ITS services, because technically, ITS is an admission to BSDC.

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In order to receive that service, though, it's considered a short-term service. [LR283]

SENATOR CORNETT: Then when...if there's a waiting list for those people, when they move out of that program, are we talking about putting them into 24-hour care facilities in the community? Or...I mean, if they need that now,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: ...aren't they going to need that in the future? [LR283]

KAREN KAVANAUGH: It depends. Again, of that set of people that are waiting for ITS services, typically it means that there is something going on in their life that's maybe a crisis, and they're natural supports are struggling. So they may come in, get intensive services. They come out with their...they will have stabilized some of their behaviors, and there's a plan to support the person. After that, it continues to be their choice as to what type of service it is that they may request after that. [LR283]

SENATOR CORNETT: I'll give you an example, and I haven't looked into it, but I've gotten a letter from someone that lives in my district that is elderly. They've had their child living with them with support services coming into the house and helping them. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: That person is significantly disabled. They...the parents feel that they need to move into some type of 24-hour care--a nursing home, a...some type of community-based program--something. And they said that they've been on a waiting list for a significant amount of time for that. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: What is the standard or average waiting time for someone that needs to be placed? [LR283]

KAREN KAVANAUGH: That I could not tell you. I don't have that information. I do have a staff person that's here in the audience who may be able to answer that question. [LR283]

SENATOR CORNETT: Okay, thank you. [LR283]

SENATOR LATHROP: Any other questions? Yes, Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Hi, Karen. In regards to oversight

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of your caregivers, do you do that with the department? How do you do that in your different departments; you know, the degree of care they need, the caregiving, you know, how they are, as far as abusive? How do you deal with that issue? [LR283]

KAREN KAVANAUGH: The oversight? There's a few layers of oversight. First of all, the community-based provider is expected to monitor their services delivery themselves. So every one of the providers is required by regulation to have monitoring systems in place. We also have service coordinators that are located across the state in communities. They also go in and provide monitoring of service delivery on a regular basis. They have routing, set times that they are required to do monitoring, but they also can go in at any time, and often do, just to stop in. And at that time they can also complete monitoring. There is a feedback loop to the provider, so that they know what they saw and can respond to any concerns that were found. And then the state also does certification activities of all of our providers. Those certification activities are completed by staff in my office, as well as staff through DHHS public health licensure. [LR283]

SENATOR WALLMAN: So you set up contract agreement with HHS, right? How do you... [LR283]

KAREN KAVANAUGH: The providers have contractual agreements, yes, with DHHS. [LR283]

SENATOR WALLMAN: Thank you. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: Senator Adams. [LR283]

SENATOR ADAMS: Do the private providers have the same kind of staffing issues that we heard about this afternoon? [LR283]

KAREN KAVANAUGH: Most of the private providers don't have the staffing issues, as far as the professional staff as was indicated at BSDC, because typically they're going to get their services, their ancillary services like speech pathology, OT, psychological supports, those are going to come through the community. So if they...I guess it depends. When I think about it, it depends on the perspective of the provider and where they're located in the state, if they're having more difficulty than not in accessing those services. [LR283]

SENATOR ADAMS: Then as a follow up to that, do we find in rural Nebraska more staffing issues than eastern Nebraska, I mean, finding those... [LR283]

KAREN KAVANAUGH: As far as professional staff? [LR283]

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SENATOR ADAMS: Yes, yeah. [LR283]

KAREN KAVANAUGH: I think that...someone had said earlier that it seems that west of about--in my opinion--west of about Grand Island or so, you start to have a less immediate access to professionals in the state. However, I know that a lot of folks travel to the larger communities in the state to get services and supports for people, as well as they'll use telehealth, if that's available. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: I've got a question on transportation, getting clients to...let's say you have a vocational opportunity, the transportation needed to get people around. Is that the state's responsibility, or the region? Or how is that all taken care of, if you're moving people constantly to services? Is that a state responsibility, or is that up to the local counties and regions? [LR283]

KAREN KAVANAUGH: To get them where? I'm sorry. [LR283]

SENATOR GAY: Well, let's say you're (inaudible) transportation issue to get to, let's say there's a work site. We have a vocational opportunity. Is it the state is paying for that or the counties? [LR283]

KAREN KAVANAUGH: We have built into our rates reimbursement for our providers. Transportation costs are figured into that. [LR283]

SENATOR GAY: Coming out of the budget of the budget we looked at prior. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR GAY: And then on some of these vocational services, or the...I think it would fall under the day and residential maybe, where jobs are set up for people,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR GAY: Is that...how are we doing on that as a state? Not enough jobs? Or is it...how is that coming along? I know, you know, there are certain things that are set up, employers are providing jobs. But how are we doing on that as a state? And then also, is there any tax advantage to those employers to do that? [LR283]

KAREN KAVANAUGH: The first part of your question, it depends on the provider. We have some providers who specialize in vocational services, where that is their focus primarily, is to develop job opportunities for people in the community. So that service is

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available specifically. We have what is called a supported employment rate that we also pay our providers, which is sort of an incentive for finding real jobs for folks, that are at minimum wage and that are up to 40 hours a week. So that has helped to improve the job opportunities for people in the state. And some folks it just depends. I think that people are always looking to develop new opportunities. Some people are entrepreneurs on their own, and that can be encouraged, as well as working through a provider helping them to find a job. As far as if there's any tax incentive, I don't know. [LR283]

SENATOR GAY: Is there a certain portion...are all portions of the state working on that? I know... [LR283]

KAREN KAVANAUGH: On finding jobs for people? [LR283]

SENATOR GAY: Yeah. I'm familiar with eastern Nebraska, but would you say it's comparatively going well everywhere, or better in certain parts, or... [LR283]

KAREN KAVANAUGH: I think everybody finds job opportunities for people that are looking for them. Sometimes those jobs are paid; sometimes they're not paid. [LR283]

SENATOR GAY: Thanks. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: I do have a few questions myself. I was trying to follow you on the statistics, and the only chart that I had was this one, and you were saying numbers and I couldn't find them on your chart. So I'm going to take a minute, if I can, to ask you a few questions that will help clarify something for me. I understand that there are two groups of people when we talk about a waiting list. There are those that have asked for services, some of which may be for services in the future, and then there are those who are past their need date--am I using the right--past their date of need. When you told us that there the waiting list had 1,772 people, those are folks who are past their date of need, is that right, and do not include the population of people who may have asked for a service in the future. Did I understand that correctly? [LR283]

KAREN KAVANAUGH: There are a total of 1,772 people who are waiting for services, yes. [LR283]

SENATOR LATHROP: That's past their date of need. That 1,772 people doesn't include the folks who have said, my Billy is 12, and I would like him in a residential setting when he reaches 21. Am I right? [LR283]

KAREN KAVANAUGH: Yes. (Laugh) [LR283]

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SENATOR LATHROP: Okay. Do you know what that...and maybe that list of people who were asking for something they don't even want yet but will want in the future, maybe that's not as important to us, other than to tell us what it's going to look like in the future. But we do know there's 1,772 folks who have said, I need something and I needed it yesterday. [LR283]

KAREN KAVANAUGH: Right. [LR283]

SENATOR LATHROP: Okay. Of that 1,772, how many want a residential setting for somebody in their family? [LR283]

KAREN KAVANAUGH: One thousand five-hundred and fifty-nine are waiting for residential services. [LR283]

SENATOR LATHROP: One thousand five-hundred and fifty-nine. So out of our list of 1,772, 1,559 of them want a family member or a loved one or someone for whom they are guardian, they want them placed somewhere where they can be...have a new home. [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: And I suppose that waiting list suggests to us that the capacity of our system, both in community-based care and Beatrice, isn't big enough to meet the needs of everybody who wants residential services. That seems obvious. Would you agree with that? [LR283]

KAREN KAVANAUGH: The capacity? [LR283]

SENATOR LATHROP: Yes. In other words, we wouldn't have a waiting list with 1,559 people on it if we had the capacity to take them all in. [LR283]

KAREN KAVANAUGH: True. [LR283]

SENATOR LATHROP: Okay. We asked you...or you were asked about how long...what's the average time people wait on a list, and you said there might be somebody here today that could tell us. If I have somebody, I made a request, and I've been waiting for X number of months, you can find that out for us? I'd be interested in that, the waiting list. [LR283]

KAREN KAVANAUGH: Don Severance is here from our office. [LR283]

SENATOR LATHROP: Maybe we'll have Don come up, after you're done, just briefly to

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answer the waiting list question. [LR283]

KAREN KAVANAUGH: Okay. [LR283]

SENATOR LATHROP: Community-based care can take on many different forms. It can be a residential setting, where they might be in a group home and be provided a job, help finding a job, and different services they may need. [LR283]

KAREN KAVANAUGH: Residential services are separate from day services. Day services are the kinds of services where a person would typically be supported in finding a job. Residential services are typically for providing supports to the individual through the hours after they would be either home from school or home from a job, so the evening hours and the weekend hours. [LR283]

SENATOR LATHROP: I want to make sure I'm not mixing these up, or maybe you're giving me a better understanding. The 1,559 people, are they looking for a place to live, or are they looking for help...some of them looking for a place to live and some of them are looking for something else? Does that make sense? [LR283]

KAREN KAVANAUGH: Um-hum. Of the 1,559, they are waiting for a place to live,... [LR283]

SENATOR LATHROP: Okay. [LR283]

KAREN KAVANAUGH: ...outside of their family home. [LR283]

SENATOR LATHROP: Outside of...yeah. They're probably young adults or middle-aged adults, perhaps, and the family has said it's time for us to place my son in a residential facility, and now they're waiting. [LR283]

KAREN KAVANAUGH: Um-hum. Yes. [LR283]

SENATOR LATHROP: Do we...I'm thinking that list can be shorter--and this is a question--but I'm wondering, is there a way to make the list shorter by doing a better job of providing day services? Are we at our capacity there? And another way to ask the same question may be this: Do we have people that get on the residential waiting list because they are not getting support for day services and they finally say, they're not coming here to help me during the day; I might as well get on the residential list? [LR283]

KAREN KAVANAUGH: I don't believe that's the case. As Jodi Fenner had testified, we serve people through a priority for funding in this state. So that's typically why people are waiting, is that they have not yet been found to be a priority for our services.

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[LR283]

SENATOR LATHROP: Okay. The process of getting on the waiting list, that involves some request, and then are they evaluated by someone with Health and Human Services? [LR283]

KAREN KAVANAUGH: Yes. They make a request. That request can come from the family. It might come from the school. They might be directed by a physician. But the fact is they're directed to service coordinators who then will determine if the person is first, eligible for our services according to the definition of a developmental disability. So once they're found to be eligible, then their name would be placed on the waiting list for what type of services that they're requesting. [LR283]

SENATOR LATHROP: Do we have a waiting list to be evaluated by a care coordinator? Or if I have a request or a need and I want to be evaluated, does that happen automatically and right away? [LR283]

KAREN KAVANAUGH: You can be evaluated for eligibility right away. [LR283]

SENATOR LATHROP: So there is no waiting list for evaluation for eligibility? [LR283]

KAREN KAVANAUGH: No. [LR283]

SENATOR LATHROP: Is a person who wants services from the state of Nebraska required to hire their own coordinator to evaluate their needs? [LR283]

KAREN KAVANAUGH: They don't hire them. [LR283]

SENATOR LATHROP: Are they required to pay for that evaluation? [LR283]

KAREN KAVANAUGH: No. [LR283]

SENATOR LATHROP: Is there any requirement that a person or a family who has a need...are they required to pay any fees or expenses or retain any kind of a consultant or person in the private sector to assist them in this process? [LR283]

KAREN KAVANAUGH: No, they're not. I guess I should state, if the person would...well, you're asking for eligibility. I believe the answer is no. [LR283]

SENATOR LATHROP: Maybe the question is more general than that, and you're...the record won't reflect this, but you appear a little hesitant as you're providing my answers, so I want to stay with the question a little bit longer. If I want services for my son or daughter and I come to Health and Human Services and I say, you know, I need to be

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evaluated or my daughter does, to see what kind of benefit she might qualify for, are there any financial hurdles I have to clear in order to get those benefits or that evaluation? [LR283]

KAREN KAVANAUGH: No. [LR283]

SENATOR LATHROP: Go ahead. [LR283]

KAREN KAVANAUGH: If you are assigned a service coordinator, you may be...they have to determine if you have an ability to pay or have a share of cost. [LR283]

SENATOR LATHROP: I don't have to pay to find that out. [LR283]

KAREN KAVANAUGH: To my knowledge, no. [LR283]

SENATOR LATHROP: Okay. So if I...the process would go something like this: I have a need, I contact HHS. They say, you'll have to speak to a service coordinator, and then there's an evaluation process, part of which is to determine whether or not I have the money to take care of this myself. [LR283]

KAREN KAVANAUGH: To get into services? [LR283]

SENATOR LATHROP: No. [LR283]

KAREN KAVANAUGH: No. No, that is not my understanding. [LR283]

SENATOR LATHROP: So all we do is look at need of the patient? or the... [LR283]

KAREN KAVANAUGH: When we're determining eligibility, we look at it according to the definition under the law. [LR283]

SENATOR LATHROP: Part of this is financial, isn't it? I mean, if I have a lot of resources and my son or daughter is 16 years old, will you say to me, you can pay privately; you don't qualify? Here's a list of people that you can talk to. [LR283]

KAREN KAVANAUGH: Oh. If you...anybody can private pay. Yes, I'm sorry. I did not understand that. Anybody can choose to private pay. [LR283]

SENATOR LATHROP: Do I have to no longer have an ability to private pay to get the services from Health and Human Services? [LR283]

KAREN KAVANAUGH: No. [LR283]

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SENATOR LATHROP: So whether you're Warren Buffett or somebody who's unemployed, these services are available to both populations,... [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: ...the rich and the poor. [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: Okay. And there's no fees or charges we have to pay for the evaluation. [LR283]

KAREN KAVANAUGH: It is my understanding, no. [LR283]

SENATOR LATHROP: And just so that I'm clear on this, we have a population at Beatrice that's 273 now? Does that sound right? [LR283]

KAREN KAVANAUGH: That's approximate; 272. [LR283]

SENATOR LATHROP: Two seventy-two? And you told us generally where we're at in the...who's receiving services, and that would be page 44 of your... [LR283]

KAREN KAVANAUGH: Who's receiving services, okay. [LR283]

SENATOR LATHROP: Yeah. We have assisted residential and supported residential, and that's about 3,000. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: Thirty-five in assisted and supported day services? [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: Four hundred and eighty in respite and sixty in community support. [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: And that's the entire population or all the people that the state of Nebraska currently serves with developmental disabilities? [LR283]

KAREN KAVANAUGH: Yes, through community-based services, through community-based services. Oh, and then you said BSDC, but that doesn't include...well,

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that the state of Nebraska serves, yes. [LR283]

SENATOR LATHROP: So we're on the same... [LR283]

KAREN KAVANAUGH: Yes. Community-based services and BSDC, yes. [LR283]

SENATOR LATHROP: Okay, okay. I just wanted to make sure I understood the statistics and the numbers, and that's all I have. Senator Cornett. [LR283]

SENATOR CORNETT: When you said there are 1,500 people on the list, and you said that a lot of them were there because they hadn't been approved yet, their eligibility hadn't been approved, correct, for 24-hour care? [LR283]

KAREN KAVANAUGH: No. They have been determined to be eligible if they're on the waiting list. [LR283]

SENATOR CORNETT: If they're on the waiting list. Okay, so we have 1,500 people waiting currently. We have 272 people in Beatrice, and in January we had how many--300? [LR283]

SENATOR LATHROP: Three zero eight. [LR283]

SENATOR CORNETT: Are we bumping people on the list to place people that are currently at Beatrice, in the community? [LR283]

KAREN KAVANAUGH: No. People... [LR283]

SENATOR CORNETT: How are we getting those people placed while we still have a list going for people that need 24-hour care also? How are they being integrated into that list? [LR283]

KAREN KAVANAUGH: The budgets are separate. [LR283]

SENATOR CORNETT: They are separate,... [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: ...but the beds are the same, aren't they? The number of beds available... [LR283]

KAREN KAVANAUGH: In the community? [LR283]

SENATOR CORNETT: ...for community-based are the same, whether they're coming

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from BSDC or from your waiting list. [LR283]

KAREN KAVANAUGH: There's not a stagnant number of beds that are available in the community. Providers can develop and open new settings as folks are needing their services. [LR283]

SENATOR CORNETT: Are they developing new beds; if we have 1,500 people, plus people at BSDC that they're trying to place? [LR283]

KAREN KAVANAUGH: If the funding is available, yes. [LR283]

SENATOR CORNETT: Is the funding...all right. The goal is generally to keep people in community or move people to community-based services, correct? [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: Do we currently have enough beds, enough community-based services, to achieve that goal? And if not, what funding do we need to do that? [LR283]

KAREN KAVANAUGH: It is my understanding that as we have been placing people from BSDC into the community, that service coordination has not been finding that they have not been able to find providers that have homes available for people to move into. [LR283]

SENATOR CORNETT: Then why do we have a waiting list? [LR283]

KAREN KAVANAUGH: Because we haven't appropriated a certain amount of money that we can spend for our services in community based. We do disburse that money out to the people who are currently being served. We can only bring people into services as we have people who drop out of community-based services. [LR283]

SENATOR CORNETT: BSDC, though, has separate funding, correct? Those people...is that what you said? [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: So you have funding for the people that are on the waiting list; you have funding there for people that are currently placed. The number of beds is approximately the same. I know more beds are not being created. Do we have enough beds for those people? Are we bumping people that have been waiting on a list out of a placement in a 24-hour care facility, to place and reduce the numbers at BSDC? [LR283]

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KAREN KAVANAUGH: No, I do not believe that we are. [LR283]

SENATOR LATHROP: Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Karen, when we're talking about people on the waiting list,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR STUTHMAN: ...that funding source, and then we've got the funding source for the people that are at Beatrice, now when the individual moves from the institution to the community-based, does the funding for that individual come from the other one, that it follows the patient, as we had stated earlier today? But does it come from a different pot? [LR283]

KAREN KAVANAUGH: Eventually that money will come from BSDC. It will be transferred into the community. [LR283]

SENATOR STUTHMAN: It will be transferred into the community-based setting funding portion of it,... [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR STUTHMAN: ...that it will follow that individual. [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR STUTHMAN: So that individual, you know, that funding stream follows that person from the institution to the community-based, and...but does it take a bed away from a person that's on the waiting list for a community-based service? [LR283]

KAREN KAVANAUGH: I do not believe that it does, again, because providers can open settings. [LR283]

SENATOR STUTHMAN: If they have funding. [LR283]

KAREN KAVANAUGH: If the person comes and has money with them to purchase services, you can have...that person, then, is able to. Often they come...it might be a couple of people that need to come together, but the provider...I have not been informed of providers not being able to serve people because they did not have homes available for those people. [LR283]

SENATOR STUTHMAN: Thank you. [LR283]

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KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: The people that are on the waiting list, they've been approved and are eligible, correct? [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: Does that mean they already have funding available for them? [LR283]

KAREN KAVANAUGH: No. [LR283]

SENATOR CORNETT: So they are approved and eligible, but they don't have funding, and it's actually the funding that you're waiting for to find them beds. [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Yes, Karen. This money, so-called, like Senator Stuthman...following up on Senator Stuthman's question. Is that for a year, or is that forever, or how does that work for the funding that follows the patient,... [LR283]

KAREN KAVANAUGH: It will be... [LR283]

SENATOR WALLMAN: ...or the resident? [LR283]

KAREN KAVANAUGH: Right. BSDC's...the budget at BSDC will be reduced to support the services for the individual who has moved out. That would not be a forever-and-ever kind of thing, because when the person comes out into the community, then they will be funded through the community-based side of things. So it's a one-time kind of thing. [LR283]

SENATOR WALLMAN: Thank you. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Karen, of the 1,772 on this list, 1,559, you said to Senator Lathrop, needed...were waiting for residential services, maybe a group home, maybe, you know,

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whatever. So 1,559 could be in a group home. Some can be in group home, some have to be in--I don't know what the term would be--but more intense situation. [LR283]

KAREN KAVANAUGH: It might be that they're living in their family home with supports. It might be that they're in an apartment or a group home. [LR283]

SENATOR GAY: But they want to get into a residential setting, like a group home. Is that what you're saying? [LR283]

KAREN KAVANAUGH: But residential services include they could be served in their family home. [LR283]

SENATOR GAY: Okay it does include. They could be in their family home. [LR283]

KAREN KAVANAUGH: So it's a wide variety of settings. [LR283]

SENATOR GAY: They just want the services. Okay, so of that 1,559, then, how many want to go to a group home, like...that are saying, hey, you know, parents are getting older. I need to go take care of... [LR283]

KAREN KAVANAUGH: I don't believe that we keep the data that way. [LR283]

SENATOR GAY: You don't keep track of that? [LR283]

KAREN KAVANAUGH: Uh-uh, not specifically what kind of service they're asking for. [LR283]

SENATOR GAY: So we've never done a recent study saying, oh, by the way, I need 150 new group homes around the state, and it's going to cost \$28 million? We don't have any study like that? Probably cost more than that. But labor issues--we can't...getting labor to go into group homes now is hard to get. So we haven't taken into account any big study to say what we really need in the future? [LR283]

KAREN KAVANAUGH: Not that I'm aware of, no. [LR283]

SENATOR GAY: There's no...okay. That's what I wanted. Thanks. [LR283]

SENATOR LATHROP: You have, with that last bit of testimony...maybe I misunderstood you. When you said they had 1,559 people on a waiting list, I thought that was to go into a home. [LR283]

KAREN KAVANAUGH: It's for residential services, and residential services are assisted or supported, so if they want assisted services, typically that's where they need more

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support. But we don't keep the numbers so that we know who's asking for assisted compared to supported. We just know that they're asking for residential. [LR283]

SENATOR LATHROP: Tell me what...define the difference or explain the difference. Which one is where you literally want to go live someplace in a home in the community,... [LR283]

KAREN KAVANAUGH: With staff there all the time, for example? [LR283]

SENATOR LATHROP: Yeah. [LR283]

KAREN KAVANAUGH: That would be assisted services. [LR283]

SENATOR LATHROP: All right. So that's where you go to live someplace else, and the supportive services is where they might come into my house in the morning and help a young person or a disabled person get...brush their teeth, get on the bus, and off to work. [LR283]

KAREN KAVANAUGH: Um-hum, yep. [LR283]

SENATOR LATHROP: And as you sit here today, you don't know, out of 1,559, you can't tell us what percent is waiting for one or the other? [LR283]

KAREN KAVANAUGH: No, I can't. [LR283]

SENATOR LATHROP: No idea. [LR283]

KAREN KAVANAUGH: No, I'm sorry, I can't. [LR283]

SENATOR LATHROP: Your job is to be the coordinator of community-based care? [LR283]

KAREN KAVANAUGH: I'm acting, yes. [LR283]

SENATOR LATHROP: Acting? [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: And you can't tell us, out of 1,559, what percent is waiting to go into...or looking for assisted residential placement? [LR283]

KAREN KAVANAUGH: I can't. I don't know if Don can or not. [LR283]

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SENATOR LATHROP: Well, he doesn't...he's shaking his head no. With 1,772 people on the list, what's the priority? How do you establish a priority among the people waiting on the list? Is it first in time, or is it based upon need? [LR283]

KAREN KAVANAUGH: It's...a person can...let's see. Let me think about this. A person has to be a priority, to be considered to be a priority. [LR283]

SENATOR LATHROP: There has to be a criteria beyond just asking to be a priority, or everybody would do it. [LR283]

KAREN KAVANAUGH: It's date of need, unless we get special appropriations. Sometimes we get...the Legislature will authorize certain...a portion of money to go to serve a specific population. For example, we recently...in recent years we had a pot of money that was going to individuals whose caregivers were elderly, so then we approached those people who were waiting for services to ask them if they wanted services. [LR283]

SENATOR LATHROP: We have no such pots at this time, though, do we? [LR283]

KAREN KAVANAUGH: No, just the day services. [LR283]

SENATOR LATHROP: So all we have now is "first in time, first in line." [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: So if we have a person with developmental disabilities, and I'll use an example that was given to us this morning by Dr. Buehler, which is a person who is going to run across the room and try to stick their head through a window. That person, if they just got on the list two months ago, they have to wait for 1,500 or 1,700 people to get their services before that family is going to get residential assisted services. [LR283]

KAREN KAVANAUGH: They can request to be considered as a priority, and that's a process that they can go through. [LR283]

SENATOR LATHROP: All right. It sounds like, unless we substantially increase funding, that the only way the line is going to move people through it is through attrition. And can you tell me what the statistics are with respect to attrition for people in Nebraska who are receiving benefits for developmental disabilities? [LR283]

KAREN KAVANAUGH: No, I can't. [LR283]

SENATOR LATHROP: Is there anybody that came here today that could tell us how

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many people actually go off the rolls of receiving benefits or services for developmental disabilities? [LR283]

KAREN KAVANAUGH: If anybody is here today that could, it would be Don Severance. [LR283]

SENATOR LATHROP: Okay. Senator Cornett. [LR283]

SENATOR CORNETT: Back to the list. You have...say, for instance, you have someone in Beatrice that they're trying to find placement for in a community-based setting. You have someone that is approved, that is on the list for funding. Who is going to get that bed? Who determines that? The bed that is available, because if there is not the funding and they're not currently...the bed is available...even private sector resources are limited. They can't just open up a bed tomorrow. They have to have staff to do that; they have to have the support. Are we trying to outsource to community-based services for...and while we have a facility open where people do have care currently--given, we need to improve that--at the jeopardy of people that are trying to find community-based services, like a 24-hour bed? [LR283]

KAREN KAVANAUGH: Right. I would say no. [LR283]

SENATOR CORNETT: When Senator Lathrop talked about the priority, when they can request a priority, how is that determined, if a person has someone that obviously needs to be placed, like the gentleman--or not obviously that particular person, but someone that truly has a need, maybe more than another person and they request a priority, how is that priority determined? [LR283]

KAREN KAVANAUGH: There is a... [LR283]

SENATOR CORNETT: And who makes that determination? [LR283]

KAREN KAVANAUGH: It is looked at locally. Each service area has a service coordination committee that takes a look at priorities in their area, and they, of course, determine if they believe that person to be a priority for funding or not. If they do not believe that that person is a priority, then that person is informed of that decision. If...and that's according to the definition under the law, as far as needing services, okay? [LR283]

SENATOR CORNETT: But everyone on the list, it's already been determined that they need services. [LR283]

KAREN KAVANAUGH: That they're eligible for services. [LR283]

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SENATOR CORNETT: That they're eligible for services. [LR283]

KAREN KAVANAUGH: Um-hum. And so a local committee will look to determine if that person is a priority one according to the law. If they believe that that person is a priority,... [LR283]

(UNKNOWN): (Inaudible.)

KAREN KAVANAUGH: Okay, thank you. I'll remind you again: The first priority of the state in responding to the needs of persons with DD should be to ensure that all such persons have sufficient food, housing, clothing, medical care, protection from abuse or neglect, and protection from harm. So the local committee will look at information that has been present to them, to make that determination. They may believe that that person has sufficient supports, even though it's difficult for the family, that they believe that person has sufficient supports. And they'll notify the family. If they believe that the person may be a priority, they would make that recommendation to Lincoln. In Lincoln we would review it again, and again look at the case, the information that's provided, and make a determination if we support that it is...the person is a priority for funding or not. There's a number of different factors that are considered in making those decisions, and it may be that we will make recommendations back to the local office, if we find the person not to be a priority, for other sorts of services that might be available to the person in their community to support them in their current situation. [LR283]

SENATOR CORNETT: Is funding specific to the individual? Say, for instance, you have one person that has higher needs than another one. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: Is funding based on individual needs? [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: So if you have a person that needs three-on-one staffing, they will have funding for three-on-one staffing, if they move into community-based services? [LR283]

KAREN KAVANAUGH: When they come into community-based services, we do an assessment. It's called the ICAP, and I believe that we're going to have testimony on that tomorrow, where we talk about the funding. But yes, we go through what is called the objective assessment process, which determines how much funding is available to each person for them to purchase their services. And then they make choices about how they spend that money, if they want residential or... [LR283]

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SENATOR CORNETT: Who is "they"? [LR283]

KAREN KAVANAUGH: The individual and their support system will decide what services they want. If they want, for example, residential services, they can decide if they want assisted services, where they get much more...the 24-hour type of support, or if they want just supported, where it's just less. [LR283]

SENATOR CORNETT: Again, back to people that require two- or three-on-one, 24-hour staffing, the people that will either harm themselves or harm someone else. If they move into community-based services--because I've heard a number of times when we were on the tour that that was the ultimate goal,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: ...is the funding there for community services to be available for that population, because it's not a choice at that point necessarily, whether they have two- or three-on-one staffing that's a requirement. They may want to choose. One gentleman we talked to said that, you know, he wants to go get a job, he wants to do this, he wants to do that. His choice and his guardian's choice might be for him to do that, but it's not in his or the community's best interest. [LR283]

KAREN KAVANAUGH: If the person chooses to come...that they want services in the community, we would go through the objective assessment process to determine how much money is available for that person to receive supports in the community. That happens for every person who receives community-based services. [LR283]

SENATOR CORNETT: Okay, thank you. [LR283]

KAREN KAVANAUGH: That is what the determination is. [LR283]

SENATOR CORNETT: Okay, yeah. [LR283]

SENATOR LATHROP: Anything else? I don't see any. Thank you for your testimony and your appearance here today. I think we're probably going to...I think the last person is going to be Mr. Severance. Is that right? That's right? Okay...who is going to clear everything up for us. (Laughter) Why don't you start out with your name. Spell your last name for us, and then give us a little background on where you fit in at Health and Human Services. [LR283]

DON SEVERANCE: Okay. My name is Don Severance, and it's S-e-v-e-r-a-n-c-e. I'm a disabilities services coordinator with developmental disability system, so I've been with the system for about 30 years, but the first 25 was down at BSDC, and the last five years have been in Lincoln with the developmental disability system, so. [LR283]

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SENATOR LATHROP: Okay. What does your job involve? [LR283]

DON SEVERANCE: I oversee the quality improvement and the funding methodology for the system. [LR283]

SENATOR LATHROP: Okay. So you're going...are you coming back tomorrow? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: We have you set to come back and talk about the formula and tell us about how much money will follow someone, depending on their needs, and how we go through the formula. [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: We won't have you do that again tonight. We'll wait until tomorrow. But we did have, it looked like, three issues that people turned to you. And one of them was the time folks spend on a list. We have 1,559 people, apparently, past their date of need or a list for residential services, and it sounded like the last...Ms. Kavanaugh thought you had the answer to how long do people wait on the list. [LR283]

DON SEVERANCE: Currently, there are people with requests back to January of 2003. So currently, there's people that have been waiting for close to 5.5 years. [LR283]

SENATOR LATHROP: And these are people who are past their date of need by 5.5 years. Do you have...is that typical of people who request residential services, 5.5 years? [LR283]

DON SEVERANCE: It varies based on, again, when there's been funding available to be able to address the waiting list. I mean, it gets shorter, and then it gets longer, you know, based... [LR283]

SENATOR LATHROP: Okay. If we currently have people that have been there 5.5 years, what's the average, sir? [LR283]

DON SEVERANCE: Probably about three, is what I'd guess. [LR283]

SENATOR LATHROP: And that's for residential services... [LR283]

DON SEVERANCE: Yes. [LR283]

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SENATOR LATHROP: ...past the date of need? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: Why are we almost two times the average right now? [LR283]

DON SEVERANCE: Because there hasn't been any funds specifically appropriated to address the waiting list since the Tobacco Settlement money. There was \$5 million back in 2001-2002, and as that money was used, but since it's long-term services, it continued to be used by the same people. And so we aren't able to bring other people off the waiting list. [LR283]

SENATOR LATHROP: So the only way someone can begin to receive...be taken off of the waiting list and start to receive services, because we're not increasing funding or haven't, is for someone to leave the system? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: Now the other question we had for you was the attrition rate. I was trying to do some math. It looks like we have about 7,000 people receiving services through the community-based programs, and we have 272 people at Beatrice. Is that our population of people receiving... [LR283]

DON SEVERANCE: There's about 4,500 in the community, when...you're adding up the day and residential. Some of those people are receiving both day and residential, so there would be duplication. [LR283]

SENATOR LATHROP: Oh, okay. So 4,500 in community-based programs, and 272 at Beatrice. Is that our entire population, or am I missing somebody? [LR283]

DON SEVERANCE: Yeah, I believe that's the state funded. [LR283]

SENATOR LATHROP: So if we have about 4,700, 4,800 people, how many people leave and make room for someone to come off the list in a year's time? [LR283]

DON SEVERANCE: Okay. Lately, it's been about 200 people, slightly over 200 that have been leaving services, a year. [LR283]

SENATOR LATHROP: And is that because they leave the state or they die, or what accounts... [LR283]

DON SEVERANCE: There's a variety of reasons. Yeah, some do leave the state. Yes, there is some attrition by death. There are some people that basically gain enough skills

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to where they don't want our services anymore, or they choose some other type of service. [LR283]

SENATOR LATHROP: Okay. So if we have 200 people leaving, they are making room for 200 people to come off of the 1,772-person list; is that right? [LR283]

DON SEVERANCE: Some of those people are graduates that left, and so the way we've been funding graduates in recent years, it has been based on a kind of attrition model, of what the net increase in graduates is. So we have like 200-and-some graduates, or close to 200 graduates that start services each year that are funded by the Legislature. But some of that 200 attrition is actually graduates that have left services over time, so. [LR283]

SENATOR LATHROP: And you use the term "graduates" for the first time that anybody has used that today, so maybe you can share with us what that means. [LR283]

DON SEVERANCE: Okay. Since...I believe it was in 1996 that the Legislature said that anybody that graduated from Nebraska high school, turned 21 and graduated from a Nebraska high school, would receive services. So they've received day services since that time. So that's the past 15 years. So anybody who is eligible for our services, turns 21, from a Nebraska high school, is able to receive day services. [LR283]

SENATOR LATHROP: I know that explanation had something to do with attrition, but I'm not sure what. (Laughter) I mean, we had...I'm not...and believe me, I appreciate your effort to explain this to me. What I understood is 200 people are leaving, and that makes room for 200 people off the list. Is it more complicated than that? [LR283]

DON SEVERANCE: Well, yeah. I think it is. [LR283]

SENATOR LATHROP: Okay, then explain it to me, if you can. [LR283]

DON SEVERANCE: Yeah, some of the people are off the list, because some of the people on the list usually are people who want day services out in the future, because they're going to be graduates. So some of those positions that...the attrition is graduates that came in, and it's filled by graduates, I guess is what I'm saying. It's not all coming off the waiting list necessarily, because they are entitled, by the way the law is written, to be able to receive services. [LR283]

SENATOR LATHROP: So we have 200 people leave for whatever reason. Do we first allocate their empty spots to people that have graduated from a Nebraska high school? [LR283]

DON SEVERANCE: Yes. [LR283]

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SENATOR LATHROP: How many of those folks do we have every year? [LR283]

DON SEVERANCE: There's about 170 to 200; it varies by year. [LR283]

SENATOR LATHROP: So that leaves room for 30 to 0 people to come off of the waiting list and actually get services. [LR283]

DON SEVERANCE: That's correct. [LR283]

SENATOR LATHROP: So that list, while it's 5.5 years old right now, is going to do nothing but get older and older and older before anybody on that list is going to get residential services. [LR283]

DON SEVERANCE: That's correct, unless there's other funding. [LR283]

SENATOR LATHROP: I think I understand it now. The split of the...I'm going to ask you this. Ms. Kavanaugh didn't know, and I'm going to ask you if you have an idea. We heard there's 1,559 on a waiting list for residential services. Do you know how many of those are actually looking for placement in what she described as assisted residential versus supported residential? [LR283]

DON SEVERANCE: I don't have those numbers with me. I could get them for you. [LR283]

SENATOR LATHROP: Do you have an estimate, though, as a percent? [LR283]

SENATOR LATHROP: Maybe you could bring that with you tomorrow and answer that question for me, if you don't mind. [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: Are there other questions for Mr. Severance? Senator Cornett. [LR283]

SENATOR CORNETT: Mr. Severance, again it goes back to a constituent. We had someone that graduated from a Nebraska high school. They left the state; when they came back, they were not eligible any longer, for 24-hour services. We had to do an appeal to your department, or to the services for that person. But I just want to be clear. Because we offer day services for people that graduate, we don't have funding left over for anyone else, basically? [LR283]

DON SEVERANCE: Yeah, most of our budget has been a continuation budget, so it's

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pretty well covering just the people that are in services, because it's long-term care, really. [LR283]

SENATOR CORNETT: And that doesn't cover necessarily 24-hour care, then? [LR283]

DON SEVERANCE: For some people it is, because they receive both day and residential, so that would cover 24 hours? [LR283]

SENATOR CORNETT: Okay. [LR283]

SENATOR LATHROP: Any other questions? I have none. I think that will do it. We'll look forward to seeing you tomorrow. And I think that concludes our hearing for today. We'll start again here tomorrow at 9:00 o'clock. [LR283]

Chairperson

Committee Clerk

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[LR283]

The Developmental Disabilities Special Investigative Committee met at 9:00 a.m. on Tuesday, June 24, 2008, in Room 1507 of the State Capitol, Lincoln, Nebraska. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Abbie Cornett; Tim Gay; Arnie Stuthman; and Norm Wallman. Senators absent: None. [LR283]

SENATOR LATHROP: (Recorder malfunction)...today, we promised it would be the day we talk about money and the fiscal side of this by way of background. But John has asked for an opportunity to us to visit with us about the waiting list and some of those issues just to clarify some of the testimony yesterday. So in the interest of having the record complete, we're going to let John Wyvill speak on the issue of the waiting list and the priority system for the waiting list. Is that the case? [LR283]

JOHN WYVILL: Okay. Yeah. [LR283]

SENATOR LATHROP: Okay. [LR283]

JOHN WYVILL: (Exhibit 1, 4) Senator Lathrop, members of the committee, my name is John Wyvill, W-y-v-i-l-l. First of all, I want to thank Senator Lathrop for the courtesy of allowing us to come forward today to give you some additional information that might be helpful to the questions that were generated yesterday. In front of all of you, you should have a little handout that we have--Senator Harms, I think it's under your coffee mug there--is a sheet. And I will work through this for you to help work on it. The heading of it is historical usage of priority one funding by fiscal year. The state Legislature had dictated by statute the priority of our department in terms of if there is a situation for a person that has immediate need, which ensure that all such persons have sufficient food, housing, clothing, medical care, protection from abuse and neglect, and protection from harm. So when you heard the discussion yesterday about the waiting list, there is a waiting list. But there are circumstances in which if they meet the statutory criteria, they will jump up to the first. So for example, if a DD client has suddenly become homeless or they've been in a very unsafe situation that requires immediate action, they will jump immediately ahead of those on the waiting list. And historically we have outlined by fiscal year starting from 2002 in the last fiscal year. In 2007, there was 118 clients that became priority one that was served. On the second sheet we have for you for your review is attrition. That gives you the idea of the number of individuals that are currently receiving services, and historically have moved off for the a variety of reasons; they may have passed on, they have moved out of state or they may no longer have been in services. And that gives you a historical perspective for you the idea of when they move off from services. Basically, with the statutory framework with the two obligations that we have to meet first. First, are the priority one and then those that graduate from high school. The next chart shows you the budget funding for students exiting out of

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Nebraska high schools who are 21 and older. And the chart down there you will see the dollar amount projected for 2008. It shows that we have 180 new students, and then 110 leaving services, reflecting a net increase of 70 additional students. And then on top of that in a 2009, we have 40 additional students. So that gives you the idea of those individuals. And that goes back to, Senator Lathrop, I think you question about the people who, in the next chart, people who have been served from the waiting year by fiscal year. And that gives you a breakdown statistically what we have in our department, the information in terms of graduates, priority ones, state wards or others that we provide services, so you get an idea of the people that ebb and flow. To follow up also, I think there was a question you were asking. A potential client may come to us through service coordination and may request services. They do a determination to whether or not they're eligible. And if they don't meet the criteria of priority one, they go on what's called the waiting list. Now, there's some circumstances that will cause them to go off the waiting list. That is determined circumstances change and they become a priority one or second is the time comes up. And what's significant when you look at the statutory framework that set us up is that the Legislature or your predecessors have said that this program is not an entitlement program, this is one based on need. So we show the most vulnerable first, and then everybody else. So when the day comes that they get the call that they're getting services, then you have to do a determination in terms of, I think what you're looking for, ability to pay or shared cost. And so that if some one family is making \$150,000, they may have to pay a portion of the bill or fiscal responsibility, and that allocates that, and then it goes down to the next person. So it just goes, so sometimes it's a moving target in terms of how much money people get based on the fiscal pay. That goes to the last question, Senator Lathrop I believe asked. If you're looking at the waiting list, if you were to waive the proverbial magic wand and eliminate the waiting list, we have crunched the numbers yesterday and a conservative estimate combination of federal and state dollars would be \$83 million to... [LR283]

SENATOR LATHROP: Say that again. [LR283]

JOHN WYVILL: ...\$83 million, combination of federal and state funds. And then I have Don Severance here and myself if you need any additional questions for further on the waiting list issues or how we came up with that number for an estimate, and emphasize that's conservative and that obviously could change. [LR283]

SENATOR LATHROP: You are...and this morning you've taken this opportunity to clarify some testimony from yesterday, and as I understood the waiting list, basically you said we have people that graduate from high school and we've made a policy decision to plug them into this system and provide them with services. And that's typically... [LR283]

JOHN WYVILL: State law. [LR283]

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SENATOR LATHROP: Pardon me? [LR283]

JOHN WYVILL: I believe that's state law. [LR283]

SENATOR LATHROP: Okay. State law, and that number is close to 200 each year. And the attrition rate that we see is close to 200 each year. So there's sort of a wash and basically what we have left is to take priority ones, which are sort of emergent cases. [LR283]

JOHN WYVILL: Yeah. But if you look at the chart, it just depends on the level of services that they need. So in the last several years, on that chart here was that person... [LR283]

SENATOR LATHROP: What page are you on, John? [LR283]

JOHN WYVILL: Oh, I'm sorry. The second to the last page, "Persons served from the waiting list by fiscal year." That just gives you a number that we took 176 graduates, 86 priority ones, 17 state wards, and 117 other. That just gives you a flavor of the kinds of transition that is moving in and out for lack of a better term, revolving door, in terms when people leave and leave, and it's not an exact one-for-one. [LR283]

SENATOR LATHROP: And that number is higher than 200 obviously. And what I understood you to say yesterday is we have about 200 people leave the system, and we have 200 graduates come in. So where are the...and you're talking about a revolving door and people coming and going. Are there some people that know, besides the 200 you said that are part of the attrition rate that are leaving or don't need services. And if we look at all the people we're providing services to, it's more than the 200. [LR283]

JOHN WYVILL: That's correct. It's very possible that the people leaving services may have a higher cost of services, and that the people coming on board may not. It may be helpful for you, just very globally and a round number to give you an idea is that for example, the average income for a Nebraskan household, I think, from the census numbers is roughly around \$34,000. A person receiving DD services, they could have a total combination in average of \$55,000 annually. And that is broken down by service coordination, specialized DD services, as well as room and board or medical costs, which (inaudible). So globally painting a broad brush, there are the clients that are on the waiting list, it is very conceivable and possible that they may be receiving other services, such as SSI or other government services on a federal or state level while they're waiting or requesting services. So it just depends case by case. So I don't want to overstate or understate, but there is also a possibility that those that are waiting for services are getting other services. They may not be getting the services that they're requesting. [LR283]

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SENATOR LATHROP: Okay. Going back to your point, if we have 200 graduates coming on and 200 people leaving every year, the additional folks that the second to the last page says that we're serving are people who we can actually serve more than the 200 that are leaving by death or by whatever reason because one of them may be at Beatrice, which is the most expensive care for one person. And when they leave, we can provide two community-based cares. Is that what you're saying or serve two clients? [LR283]

JOHN WYVILL: That's a possibility. So hypothetically, let's say there's a client out there that is getting \$100,000 in services. Then we'll go through the waiting list of the person that is requesting services based on a thing, they may only need \$25,000. So you take that one, someone else may need \$35,000, you take that one, there may be one that takes a significant increase, just depending on what they're requesting. So it's, Senator, somewhat of an inexact science. [LR283]

SENATOR LATHROP: If we look at this, and still on the second to last page and using 2007, the actual number of people that we're taking off this list of 1,559 is 86 in the last year. Is that right? Those priority ones came off the waiting list. [LR283]

JOHN WYVILL: That's correct. [LR283]

SENATOR LATHROP: So is that a fair average for what kind of a dent we're making in the waiting list that now sits at 1,559? Is it about 85 to 100 a year? [LR283]

JOHN WYVILL: I think for the 2008 numbers which will come out after the end of this fiscal year, you can see the trend. I can't accurately predict, but I can use this as the trending data I can give you that. Hopefully that answered your... [LR283]

SENATOR LATHROP: Well, I'm looking at the trend just on this graph, and it looks like 86 last year, 105 the year before, 89 the year before, 82, 70, 79. It doesn't look like it's trending anywhere. It just looks like it's staying with more or less between 85 and, say, 70 and 100. [LR283]

JOHN WYVILL: Um-hum. That's correct. [LR283]

SENATOR LATHROP: Yesterday we had somebody testify about the established goal for reducing the waiting list to zero. And I think since the consent decree, that's been moved and we seem to say, well, we're not going to make the goal, so we're going to move it three years. And the next benchmark is in 2010. And it... [LR283]

JOHN WYVILL: Set out in legislation. [LR283]

SENATOR LATHROP: Yeah. Our goal legislatively is to have that down to zero by

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2010, not going to happen unless we do something significantly different. Would you agree with that? [LR283]

JOHN WYVILL: That's correct, Senator. [LR283]

SENATOR LATHROP: If I can, you have two more columns here. One is state wards, and the other column is in yellow and it says "others." Who are those people? [LR283]

JOHN WYVILL: Okay. Don? [LR283]

DON SEVERANCE: Those people... [LR283]

SENATOR LATHROP: The record should reflect that we now have Mr. Severance answering that question. [LR283]

JOHN WYVILL: Okay. Sorry. [LR283]

SENATOR LATHROP: I want to make sure that the record reflects what's going on. Go ahead. [LR283]

DON SEVERANCE: Okay. Actually, that's from tracking the funding for...there was \$5 million that the Legislature appropriated in 2001-2002 to serve people off the waiting list. That hadn't been tracked real well. And then we got to where we tracked it. And so that's what we're using to be able to take additional people off. [LR283]

SENATOR LATHROP: But when we have this purple column. [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: It says "state wards" under the legend, and last year it was 17 people. Were they on the waiting list or are they coming from some place else? [LR283]

DON SEVERANCE: No. They had requests on the waiting list, yes. [LR283]

SENATOR LATHROP: Why do we have a separate column for them? [LR283]

DON SEVERANCE: Because generally they're funded through child welfare, and so it's passed through DD services. [LR283]

SENATOR LATHROP: Okay. So they have a separate column because of the funding. [LR283]

DON SEVERANCE: Yeah. [LR283]

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SENATOR LATHROP: But you think they were part of what used to be a waiting list larger than 1,559. [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: And in the last column it says "117," and the legend says "other." Who are those folks? Are they just people that needed a little something and... [LR283]

DON SEVERANCE: Those are ones that we took off with that tobacco money. So they would have been the people that were waiting the longest who we'd offered services because we had extra money left over from that \$5 million so we could take people off. We get \$5 million every year from the Legislature for that. And so if we don't use it all, then we take additional people off. [LR283]

SENATOR LATHROP: Okay. Then going back to this chart to make sure I understand it, we had a list of 1,700-and-some people, is that right, all past date of need? [LR283]

DON SEVERANCE: Yes, currently. [LR283]

SENATOR LATHROP: And so the number of people that we served off of the waiting list, which is people who are past their date of need, would it be the sum of these three columns--the tan which is priority one, the purple which is state ward, and the yellow which is other? [LR283]

DON SEVERANCE: And also the green, the graduates. They were all had requests, and so they all came off the waiting list. [LR283]

SENATOR LATHROP: But the...okay. The answer's, yes, and now I want to go back, if I understand it. I want to talk about the people in green. We bring them on. They're not actually past their date of need until they graduate, right? So we put about 200 people on that list and take 200 off of it every year. [LR283]

DON SEVERANCE: Yeah, yeah. And people...I don't want to get confusion between the attrition numbers and these numbers. Some of these people are already in services. They're requesting additional service. So they may have come off the waiting list, but they may have been receiving one service and got another service off the waiting list. So you can't necessarily say that these offset the attrition numbers. [LR283]

SENATOR LATHROP: Okay. [LR283]

DON SEVERANCE: Okay. [LR283]

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SENATOR LATHROP: Mr. Severance, what I'd like to understand before we let you go this morning is if we have a goal to eliminate the waiting list and we now have 1,772 people who are past their date of service, how much over the past 5 years, how much do we reduce that list or increase that waiting list each year? Is it getting smaller by 25 or is growing by 50 each year? [LR283]

DON SEVERANCE: It's growing. [LR283]

SENATOR LATHROP: And tell me by what number is it growing each year? [LR283]

DON SEVERANCE: Since we were able to use the tobacco money, in the last three years it grew slower. Now, it's probably growing somewhere between 200 and 300. [LR283]

SENATOR LATHROP: So the 1,700 is going to be 1,900 next year unless we do something different. [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: That's all the questions I had. I think that clarified if for me. Anyone else while we have them here? Senator Adams. [LR283]

SENATOR ADAMS: Well...go ahead and let the other senators. I want to think through a couple of things a little bit more first. [LR283]

SENATOR LATHROP: Okay. Senator Cornett. [LR283]

SENATOR CORNETT: There was something that Senator Lathrop brought up that brought a little confusion to what Ms. Kavanaugh testified to yesterday. When we were asking about people on the waiting list that needed to be approved for funding, and when they were approved, that was separate funding from the people that we're currently at BSDC, that those were two separate funding streams. [LR283]

DON SEVERANCE: That's correct. [LR283]

SENATOR CORNETT: Senator Lathrop just asked, well, if someone goes out of BSDC and they were using \$100,000 worth of services that that money might be split up between someone that needed \$25,000 and another person that needed \$30,000. There was a disconnect there. [LR283]

JOHN WYVILL: I was taking Senator Lathrop's question as a hypothetical if someone was getting \$100,000 from community services and they (inaudible) off, the funding for

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BSDC is in a separate pot. [LR283]

SENATOR CORNETT: That's what I thought. That's why you... [LR283]

JOHN WYVILL: And what happens when the clients transition to BSDC from BSDC to community, we had legislation last session that the money followed them. [LR283]

SENATOR CORNETT: The person, yes. [LR283]

JOHN WYVILL: So that pot of money, and then you're talking about the reference that Senator Lathrop was using, what if we have globally a client of that. In addition, to follow up I think on another question that you had in terms, there are certain appeal processes. So if someone is on a waiting list and feels that they have priority one, they can go through the administrative appeals process. [LR283]

SENATOR CORNETT: Appeals process. [LR283]

JOHN WYVILL: They can also go through the administrative appeals process if they dispute the level of services that's being proposed. So it is not...there are processes in place to ensure the due process rights for the clients if they're on the waiting list and they feel that it's not appropriate. [LR283]

SENATOR CORNETT: Let me ask one more question dealing back with what we were discussing yesterday. Again, with what Ms. Kavanaugh testified to, the goal that you have set out for BSDC is reduce the population to--what was it?--250. [LR283]

JOHN WYVILL: Yeah, 250...I mean, 200 by the end of the year. [LR283]

SENATOR CORNETT: Two hundred by the end of the year. What is the major obstacle? Is it placement or finding people to be placed from BSDC currently? [LR283]

JOHN WYVILL: There's a couple of challenges. The first and foremost challenge is the guardians and the guardians and family members because they feel that they're getting good services, the level one is being treated well, and that they don't want to leave what they know to a community-based provider. So the biggest challenge for us is educating them about that. The other challenge is there are clients at BSDC which we feel can be better served in the community, but for guardian opposition. And that comes a very challenging, as all of you know that have elderly parents or children is how is it going to be received when we look them in the eye and tell them that we know better than you what's in the best interest for your loved one. So that's part of the discussion they had yesterday is where do you draw that line in terms of that they start acting contrary to the best interests. That's the number one obstacle. The second challenge is making sure that we have an appropriate safe placement, and that takes time. But we have to either

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work with...yeah. [LR283]

SENATOR CORNETT: Oh, no, go ahead. [LR283]

JOHN WYVILL: ...either work if the guardian had requested a nursing facility or a nursing level of care, we will work with them, they get a pass all, they get eligible for that. Sometimes they are, sometimes they they're not, and then if they're not, that's the only one that the guardian would consider. We are also working with a couple of providers to enhance capacity, that what we do is we're working with one provider that will take a higher level of risk. In a pilot project, a higher level risk behavioral client out, and they will go from BSDC into the new group home that's created. And then a level of funding will gradually go down to the community-based funding level that they would have been doing with other than community-based. And there's two or three, the one provider that we're working with informally that is contemplating adding additional group homes. So that is the biggest challenge. The second is insuring them that if they have, some of the clients have behavioral flare up, that there are some support networks that they can come back to BSDC and IPS to make sure that they can manage that behavior. [LR283]

SENATOR CORNETT: So just so I'm clear on this, the guardians, which I understand, have opposition to the people, their are family members being moved. [LR283]

JOHN WYVILL: Um-hum. [LR283]

SENATOR CORNETT: But secondly, you do not currently have places for them to go that have...you're working on finding facilities for people, am I correct? [LR283]

JOHN WYVILL: We're finding facilities. For example, we will have a person that has been approved to go or a guardian has signed off to go to a certain DD provider and they may be waiting for a bed to clear up because someone is getting ready. [LR283]

SENATOR CORNETT: That brings me back to what Ms. Kavanaugh said yesterday. [LR283]

JOHN WYVILL: Okay. [LR283]

SENATOR CORNETT: She said that as long as there was funding, there was beds available. Are there beds available or do we have to wait until you find a provider that is willing to expand their services to take people based on the fact that they have funding? [LR283]

JOHN WYVILL: Yeah. We have...I'm trying to wrestle with how to answer your question because it's on a couple of different levels. When I talked to the providers, there

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was...the providers are telling me, and I think with several in the audience here too, but the providers that I've talked to have talked my staff is and their discussions have been more on can you sweeten the pot for more funding or more money so we can serve these clients because of maybe the behavioral issues or we want a little bit more money to help these clients. Then there comes the other question of those that have the gifting resources that's just a question of where they're going. Right now we are not running into a organized or a group of every door is closed. There may be situations where two or three individuals may want to go to one provider or that one provider is at full capacity or waiting for somebody. There is like, for example, I think Encore or something to...you know, that certain providers that if you don't take that opportunity, it may not be offered any time soon because of the unique medical services, the services that are being provided. From my thing that from what I understand is that nobody at BSDC that's wanting to get out that we can't find a place for right. Now, that could happen in the future that we may have a situation down the road where we can't find any beds in Nebraska. That has not happened yet. [LR283]

SENATOR CORNETT: Okay, because you were here when Ms. Kavanaugh testified that she didn't feel that there was a shortage of beds or there would be if funding was available, that the providers would make room for people or expand their services. If the Legislature waived their magic wand and gave you the money to eliminate the list, would we even have the community-based services in place to provide care for the people that we're talking about? [LR283]

JOHN WYVILL: I think there would be a combination of having to build capacity and going in right now. [LR283]

SENATOR CORNETT: And the reason I ask that is, and I'm sure other people on the committee have heard this, is the trend is to move to community-based services, but we keep hearing that we don't have enough community-based services to provide help for all of the people that are on the list and BSDC in the state and that moving to community-based is going to be a difficult challenge because of that. [LR283]

JOHN WYVILL: Yeah. Yeah, some of the challenges, Senator, and that's a very good question, some of the challenge is it depends on what kinds of clients you're talking about because you will hear later on during the hearing of those about dual diagnosis. [LR283]

SENATOR CORNETT: Correct. [LR283]

JOHN WYVILL: The dual diagnosis, very challenging for the provider. The providers that I have talked to, it creates a challenge because you may have six or seven employees that are working in a group home for a provider. They may have to assign, because of the behavioral challenges, one or two individuals, their best employees to

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work on that client. That can be very demanding and trying, and that prevents those two from training the ones that come in. So we have that issue in the community. We also have the issue of in terms of capacity building, dual diagnosis. That's why for our longtime goal at BSDC, we want to expand the ICS program from 8 beds to 16 beds. I think the providers and I and our department may disagree on a lot of things. But one thing we can agree on, if you're asking the provider if they expand that capacity, they would welcome that because that provides an additional resource there. So I don't want to mislead you or any members of the committee. It just depends on which capacity because the people that we feel that would most benefit for community-based services are the ones that have the adamant guardian opposition, and they could be gone just like this. We could have maybe 25 to 50 out right away because they would be able to walk in or go into a facility but for the guardian opposition. And it's a very, as you heard from testimony before, very emotionally charged issue that has to be handled very diplomatically. Yes, we do have the authority to discharge someone. But I have not chosen to exercise that option because of the various things because we want to work with the one voluntarily. Now, are we going to do that in the future? I can't tell you. [LR283]

SENATOR CORNETT: Thank you very much. [LR283]

SENATOR LATHROP: Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. John, on the waiting list and the graduates, when you talk about the graduates, are these individuals going to be receiving services after they graduate or are a portion of them getting services while they are in school? [LR283]

JOHN WYVILL: Graduating. [LR283]

SENATOR STUTHMAN: They're not ones that have been receiving any services? [LR283]

DON SEVERANCE: There might be a few that are receiving residential services. They'd received day services once they graduate. [LR283]

JOHN WYVILL: And Senator, that would goes back to a question that I think Senator Adams brought up yesterday when they were asking I think Bruce Mason about the public school system. Some of the challenge that we have, yes, the school system has much more resources than we do, but some of the challenges that we have is that occasionally there are differences of opinion from the department--and we're in agreement with Nebraska Advocacy Services on some of these cases--is that some of the public schools may only not provide all the schooling or services that we think is appropriate for them. So they may make a decision not to provide certain things that we

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think that they might. So in the absence of the school, we sometimes have to step in and that comes into a disagreement about the Special Education Act and things like that. So that's gets a very complicated thing because some of the DD clients may pose a difficult challenge for in a school setting and, you know, the schools may think, well, study hall may be appropriate one hour a day, and we're like, well, if the community includes and we think you need to do more. In the absence of then doing that, we can't push that issue. The parents have been in absence of that. The have to step in sometimes and provide services and service coordination. [LR283]

SENATOR STUTHMAN: So of these graduates while they're in the school, the way I understand it, the school is providing some of the services and you might be providing some of the services, and then after they graduate from the school, then those are the ones that you are responsible for the service. [LR283]

JOHN WYVILL: Correct. [LR283]

SENATOR STUTHMAN: Okay. Thank you. [LR283]

SENATOR LATHROP: Senator Adams [LR283]

SENATOR ADAMS: If you guys will be patient with me, you've probably already answered my questions, but I've got to get it clear in my mind and they're going to come from three different directions. All right? My first question: Yesterday, I heard that because of Supreme Court opinions that the word is "entitlement." But what I heard you say earlier because of legislative action it's not "entitlement," it's "eligibility." Is that correct? Am I hearing that right? [LR283]

JOHN WYVILL: That's correct. If you look at the statutory requirements, it's an eligibility program, it's not an entitlement program. And that is our position. I believe, you guys may want to have legal counsel look at that too. But... [LR283]

SENATOR ADAMS: All right. So one of the things we're going to have to wrestle with here is that language. [LR283]

JOHN WYVILL: I mean, that's why we gave the presentation about the statutory law and the framework which we operate on. There are some out there that feel that this is an entitlement program. We wanted you to be aware of this because it's commonly known among legal circles is that lawyers, myself included, love to quote Robert's Rules of Order, yet maybe in a room of five lawyers, only one lawyer may have read Robert's Rules of Order. So what we wanted you to be aware of is that statutory framework so you can make a decision yourself. But we feel it's not an entitlement and it's very clearly stated out in our statutory authority. [LR283]

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SENATOR ADAMS: Okay, and that eligibility, the priority--I'm looking at the front page of this--you have defined here for us what first priority constitutes, what that means. [LR283]

JOHN WYVILL: Um-hum. [LR283]

SENATOR ADAMS: Okay. [LR283]

JOHN WYVILL: That's the statutory definition there. [LR283]

SENATOR ADAMS: All right. Now let's shift gears. I'm going over here to guardian opposition to someone leaving Beatrice. It could be for a variety of reasons. If a...let me get right to it, is the private provider paid at the same rate as what Beatrice would be? [LR283]

JOHN WYVILL: No. [LR283]

SENATOR ADAMS: So is it possible then that the guardian is saying I don't want them to leave because if they go from Beatrice to private provider A, A isn't going to provide the same services and one of the reasons they aren't is because they're not getting paid at the same level that Beatrice would be. [LR283]

JOHN WYVILL: That's correct. One of the issues is that at BSDC when you have the budget presentation later on is everything is provided on campus. [LR283]

SENATOR ADAMS: Um-hum. [LR283]

JOHN WYVILL: In the community, they have to go to the grocery store, they have to go to the dentist, they have to go there. We have our own dentists and we have our nurses and we have active treatment on campus. So that is the contrast though when you see the numbers, you will see the difference in the cost per client cost up there. That is why you will see folks like Mosaic want to have the same pay as we have with the ICF/MR, and that's why you see the provider come back and say, we want to get paid like your staff and we want to have those things. So that's part of the challenge. The guardian opposition is, from my perspective, a mixed blessing. The mixed blessing is they are actively adamant that the--by and large to everyone I've talked to--is that the client that they...they're being well cared for while taking care of why should I leave, why should I leave for the fear of the unknown. And the fear of the unknown also is a complex issue because it's a very delicate issue because you have guardians that are in their sixties or their seventies, starting now to think about making the will to providing in the future. They know what they are getting at BSDC and are comfortable with that. They're kind of...despite what we tell them, so we have to work with...we have been working with ARC of Nebraska and others as DOJ has suggested--Department of Justice

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suggested--to do a better job of educating them about the successes and the positives of the community-based services. Now, there's some clients at BSDC that we think we can better serve them at BSDC than in the community. So that's the mixed bag that we're under. [LR283]

SENATOR ADAMS: Okay. Thank you. One more question regarding the high school graduates. I'm going to digress for a moment. And we had some legislation this year that I felt was unfortunately necessary. Having to do with allow people with disabilities to walk across the stage and get something resembling a diploma, even though they're going to stick around until age 21. If a high school decides to graduate a person with developmental disabilities, they've decided to graduate them as part of their IEP plan and they're going to graduate them at age 18 or 19, when they graduate, do they then lose their funding and pick it back up at 21? [LR283]

DON SEVERANCE: Yes. Yeah, we don't serve them until they reach their twenty-first birthday. [LR283]

SENATOR ADAMS: So there is this gap then where they're unserved. [LR283]

DON SEVERANCE: Yes. [LR283]

JOHN WYVILL: Unless they're a priority one. [LR283]

SENATOR ADAMS: Unless they're a priority one. So from the school's standpoint, they have met their educational plan, hence they could graduate. But we're not going to because if we do, we're going to lose funding? [LR283]

JOHN WYVILL: There's a difference of opinion sometimes between the Department of Education and our department in terms of whether or not..well, for the school district, rather than whether or not they really graduated because our perspective is, as anyone else is, is that the more early intervention that you do, especially with DD or anything with disabilities early on is very similar as, you know, from economic development. High school diploma and college diploma, different earning capacity. So what you invest from K-12 is critical in the advancement of a person with a disability because that gives them the opportunity whether they succeed or fail. That gives them that opportunity in which they can realize the fullest potential that's been afforded this on the Nebraska flag, which is equal before the law. And that's where it needs to be done. And that's the biggest challenge. And then instead of speaking globally, there's a check on a table for the lunch and then every just working around about who's going to be picking up the tab. You know, though it sometimes becomes a question of that. We could call...we have I think about ten clients that are currently getting high school at BSDC, and then they're the...you know, there's a question does the school district object to having to pay for that, even though they're not longer in the residence. So that's a very difficult issue.

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Stepping apart from the financial issue, it's about the opportunity for that particular client whether they succeed or fail may hinge largely on their high school education to give them that opportunity. [LR283]

SENATOR ADAMS: Yeah. Okay. Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Thanks. John, I've got some questions to clarify the waiting list, some of the things you had mentioned. And of the 1,559 people, you said it's \$83 million in federal and state funds if we were to totally wipe out the list today. [LR283]

JOHN WYVILL: Um-hum. [LR283]

SENATOR GAY: Okay. Then I think you said you don't know exactly what benefits some of these people are receiving on the waiting list. [LR283]

JOHN WYVILL: When we're talking about what might have been an impression conveyed by the various people that testified before hear that DD services are the only services that they may be getting. When they're on the waiting list, then they create...we don't want to mislead you, but we want to make sure you understand it. If they're on the waiting list, there's a very real possibility that other services they're getting either from the state or the federal government, whether it be SSI or other government programs and wanted to give you an accurate picture depends on case by case. And that's what we wanted to give you a snapshot, compare it to the average Nebraskan household income, the average number of services that we get for our clients, and then those other services that they might be getting. [LR283]

SENATOR GAY: Okay. So if I had a spreadsheet showing 1,500 people on that list, I could say they're getting SSI, they're getting these benefits. You can tell us that if we really wanted to get into this list. [LR283]

JOHN WYVILL: We can go and individually check, if you like. [LR283]

SENATOR GAY: So we are tracking all these things. [LR283]

JOHN WYVILL: We'd have to go and check, but we... [LR283]

SENATOR GAY: And you think we're tracking them though. Do you...I mean, the reason I say that, if I had a list of 1,559 people and I wanted to start clearing it up, I may look at the ones, the low hanging fruit maybe and say, well, they just need a simple service that we have. Why wouldn't I take...you know, I understand a priority, but maybe some of these people just need one or two things that wouldn't be all that costly, but we start

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whittling away at the list. But we couldn't do that unless we know exactly what they're getting, and then the request. So on that list, you also have what their requests are, right? [LR283]

JOHN WYVILL: Yeah. We have...they may come in and ask for A, B, C, they say we want A, B, C, we want three things. And then once they look at it and they say, no, just based on what you're looking at, based on what we're going to be talking about later with the objective assessment process and the formula and how we distribute the money, they may not be getting all that they're requesting. So it just depends in terms of the DD services, in addition to whatever else they get, in addition to the financial assessment. [LR283]

SENATOR GAY: But they may be getting a portion of...if I'm requesting for a...let's say you got five services, I've requested for all five, I'm receiving two. I'm still on the list because I'm still waiting for three others that I may or may not get. [LR283]

JOHN WYVILL: That's correct. [LR283]

SENATOR GAY: Okay. So if I'm waiting for a vocational thing where it takes me out during the day and I'm working on a job, but I come back home at night, those things are to me if we had jobs available, we could fill those. Maybe there's 150 people on that list. So are we actively, when you're looking at the list and it's actively moving, it probably never is going to go away because you're people keep requesting more services. It's never really going to get down to zero is what I'm saying because you're going to keep requesting more services. We can do a better job probably on that list. But I guess I'm just wondering, to make sure we know that I need these three services and I'm getting benefits on these five services, that there's some coordination out there. Do we have a computer program that tells us that or some system we bought? Is it just manually done or how do you do these things? [LR283]

DON SEVERANCE: Yeah, I'm not that familiar with...I know it's tracked as far as Medicaid will track all the expenditures. So it is possible to crosslink databases and figure out how much benefits people receiving from SSI or other things, so it is possible. [LR283]

SENATOR GAY: Well, that's just something that kind of concerned me yesterday when I heard about this list and we weren't sure and, you know, that throws up a lot of questions. But I think in today's day and age with data that we can process that we should be able to at least cross reference who's getting what at this point. And that we should probably work on that in the future to say, well, I'm getting three services and I know exactly what they're getting. Otherwise, fiscally it's like it's hard to throw money into something when I'm not so confident it's going to be utilized fully. But I think that's something that we need to work on as a department in general. Thank you. [LR283]

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SENATOR LATHROP: I do have a couple of follow-up questions. And actually maybe to start, I'll clarify because Senator Gay was using the 1,559. The waiting list is actually 1,772; 1,559 represent the number of people on the waiting list looking for residential services. Am I right? [LR283]

JOHN WYVILL: That's correct. [LR283]

SENATOR LATHROP: And yesterday we had a conversation, I was trying to get an idea of how many of those people were looking for a place to live versus looking for services where they come into the home and make sure that they get their hygiene things met and fed and on the bus to go to a job. Did you... [LR283]

DON SEVERANCE: So there's about 52 percent of them were looking for assisted services where you'd have continuous staff. [LR283]

SENATOR LATHROP: Okay. So just so that we're clear, assisted services is the essentially a place to live where you live in a group home or you're in Beatrice. [LR283]

DON SEVERANCE: Yeah, or extended family home, yeah. [LR283]

SENATOR LATHROP: Okay. So of the 1,559 that are on the residential waiting list, 52 percent of them are actually looking for a place to live. [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: And that would be the most...will talk about the finance piece of it. But if we look at blocks of care that we provide to these folks, that's the most expensive block of care. Am I right? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: I mean, we can give bus services to somebody or dental services, those are relatively small units of care, but this is the expensive, so they're more likely to sit on the list longer because of the money. [LR283]

DON SEVERANCE: In the past, like with the tobacco funds that the Legislature said that we would serve those who had been waiting the longest, so it has been based on how much it is for the service. It's really been based on how long they've been waiting for the services. [LR283]

SENATOR LATHROP: Again though, do the...if we have 1,550-some people and 52 percent of them, so what are we at? About 800 people that are waiting for that. [LR283]

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DON SEVERANCE: Right. [LR283]

SENATOR LATHROP: What's the average they've been waiting for that kind of a service? Is it still three years like everybody else on the list? [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: And are there some people that have been waiting as long as five and a half years or more? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: The goal is to get the--and now maybe I'll direct this to John--the goal is to get the population at Beatrice down to 200. That's the stated goal in order to have the staff and the number of residents in the right proportion. [LR283]

JOHN WYVILL: Um-hum. [LR283]

SENATOR LATHROP: That's the reason and that's the goal, is that true? [LR283]

JOHN WYVILL: That's what we're trying to head to. Yes, sir, Senator. [LR283]

SENATOR LATHROP: Okay. As you reduce the number of people that we have at Beatrice, are we letting anyone in or have we closed the gate at Beatrice to the people with the high needs that we've heard described by Dr. Buehler yesterday? [LR283]

JOHN WYVILL: There has been over the last couple years, there's been insinuating circumstances when someone has been admitted to BSDC. Most recently we had one this year, two that I'm aware of this year... [LR283]

SENATOR LATHROP: How about this one if you can answer this for me, John. As we ended the session, we had a population of 308. [LR283]

JOHN WYVILL: Yeah. [LR283]

SENATOR LATHROP: And we saw the Governor's plan was to reduce the 308 down to 200. [LR283]

JOHN WYVILL: Yeah, my plan. [LR283]

SENATOR LATHROP: Your plan. Okay. Presented to me by the Governor. Your plan was to get us down to 200. Have we taken in a person to Beatrice since we were at 308

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and on our way to 200? [LR283]

JOHN WYVILL: There have...not knowing the sequence of time, there's two that I'm aware of this year in which we admitted someone into ITS program in which we couldn't have two clients in the same living unit for health and safety reasons, so we had to move one out. And then second was there was one, there was another one--without going into client confidentiality--another one that we had to admit because the guardian was adamant for admission. [LR283]

SENATOR LATHROP: But the ITS, just by definition, the ITS is a short-term stay at Beatrice. [LR283]

JOHN WYVILL: That's correct. [LR283]

SENATOR LATHROP: So we're not...if there is someone on that list who is a safety risk, does that make them a priority one? Can you be a safety risk without being a priority one? That's more housing and basic needs, am I right? Priority one. [LR283]

JOHN WYVILL: Well, in the particular context that I was talking about, Senator, we have an eight-bed facility, and one that was requiring an individual requiring services. Because of the circumstance, it could not be in the same living unit as another, which necessitated the need of transferring one or admitting one into the main ICF/MR for... [LR283]

SENATOR LATHROP: Okay. Okay. But it came into the ITS program. [LR283]

JOHN WYVILL: Yeah. [LR283]

SENATOR LATHROP: I think that's all I had. Senator Harms. [LR283]

SENATOR HARMS: Thank you. John, could you provide us an organizational chart of Beatrice? [LR283]

JOHN WYVILL: Sure. [LR283]

SENATOR HARMS: That would help me probably have a little bit better understanding of how this organization works and who reports to who would be very helpful as we go ahead and begin to look at this entire issue. John, I guess the...we're spending time here, and rightfully so, discussing those folks who, people who are on the waiting list, and I'd like to see that resolved in some form or manner. But you know what really where my main concern is, even if we were able to resolve this--okay--when I look at the U.S. Department of Justice report, and I keep coming back to this because this is the heart of the this issue, and I don't want to lose sight of this because I have great

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doubts of whether we can manage this. Okay? And when you look at what's there and what the findings were, my concern is do you have a plan put together to correct this? Secondly, are we going to be on target to be able to deal with this issue, you know, appropriately in the future? If you shift to moving as many people that you want to move from Beatrice to a community-based program, I fear that we don't have the things set up right or that it's going to be dealt with appropriately because everything else that's in this report leaves me to the conclusion--and it might be wrong, I don't know--that we are not going to be able to manage this. You're going to place people into that services for those services in a community-based program that we may not have adequate support for. And so that's the issue that I have and that's the thing that I will keep coming back to is the management of this program and the management of Beatrice because that's the heart of the issue here. And when you read it, and I've read this thing three or four times, it's very difficult for me to even go through it. How do we cover the rifts of that issue because that's going to be the heart of this and that's where we're going to have to really get down and deal with the issues. What is your plan to address these issues? How does it all fit together in regards to straightening that portion of that because you come from a premiere program to one that is not there that said. And so that's kind of where I'm coming from and I would really like to hear what your view are about what I've posed to you. [LR283]

JOHN WYVILL: Well, first of all, Senator, I want to thank you for the opportunity to be able to answer that question. We have outlined, our plan is basically very straight forward. What we have done, first of all, is that we have brought on temporary...first of all, we want to be reducing the census down to make sure that we have the staffing in a ratio that we're comfortable with. Even though that we meet the minimum federal staffing ratios, we feel that if we reduce the ratio, and we're starting to see dividends of that, when we first started right sizing the population of BSDC it was 326; as of last Friday it was 272. We have closed three living units. We're anticipating closing another one this month, and another in fairly short order. That consolidation and merging of living units has also allowed the staff to be reallocated, in addition with the temporary agency staff working. We have seen mandatory overtime go from our numbers from 650 hours down to 93. In the last report appears that I have seen, we have seen an increase in the number of employee complaints for voluntary overtime being threatened now because we're doing a better job in terms of managing the direct care staff. We are also and have done some reorganization within BSDC in which we're adding enhancement to management that can talk about not only the staffing issue that we need to enhance in terms of direct care staff, we also have professional staff that we're enhancing. We're going to be bringing on a residential manager is going to be national recruited. We're going to be bringing on an added investigator. We're going to be bringing on a quality management, someone to challenge it, not of BSDC's fault and the staff fault. There are some good and dedicated people that work there, but there may be a collective missing pieces to the puzzle in terms of national accepted practices. One of the things that we have done so well, we brought on Liberty that helped identify, Liberty Health Care, the

head nationally recognized best practices, has recognized some of those issues. So the pieces of the puzzle are coming together in terms of we're dealing with directing the direct care staff, we're addressing the professional expertise. Department of Justice in our informal conversation with them alluded to in their letter have indicated that they like the direction. I can't speak for CMS, but in terms of nationally across the country, the reducing of people living in ICF/MRs is as stated, federal public policy in various different components. It may not be stated by a CMS, but they do that by the regulatory and based on informal components. So the plan, as you will learn through the process in the next two months of testimony, is that some of the problems were two decades in the making, some were shorter. And we're taking aggressive steps that we're starting to pay off in terms of enhancing our management, enhancing our professional staff, enhancing our direct care staff, reducing the census. And the bottom line in the role of an ICF/MR is from what it's supposed to be doing and the proper purpose of it, it is a temporary place. It is simply unacceptable that someone in ICF/MR has lived there for over 32 years. You know, that is not the role of an ICF/MR. And there was a day, there was a time in which, you know, we still have parents come forward and say, what's this active treatment stuff? They say, we just want our kid to get three square meals a day and sit in front of the TV. And that, you know, nothing bad happens to them. That's all they want. You know, we're working very aggressively. Obviously, in a 24/7 facility, you always have to continue to improve or always working and doing enhancement to enhance the safety of our clients and enhancing active treatment. So when you hear the testimony that you will hear in July and August, you will see a very clear chart course, and just a question of executing and having that time. And whether or not that Department of Justice and CMS finds that acceptable. [LR283]

SENATOR HARMS: Two more questions, John. What plans do you have in regard to when you make all these plans you move in the direction, you also--and I mentioned this yesterday just briefly to your CEO--how are you going to change the culture of the organization? And what kind of effort are you going to make in getting people to understand the level that you want and the quality that you expect? Sometimes just bringing new people in doesn't always cut it. The people have to change and be willing to change and to provide the right services. So what are we looking at in regard to the cultural change? What kind of staff do we (inaudible) ? [LR283]

JOHN WYVILL: I think we've adopted a zero tolerance policy, treating people with dignity and respect, actions speak louder than words. I think in terms of the culture that they allude to is that, as Senator Lathrop and others have read on the floor of the Senate (sic), there are individuals unfortunately that have used to work in our facility that have treated our clients less than human beings and that's not acceptable. You have to have consistent application of those policies to ensure that that happens and that kind of action, a lot of them would, those bad apples, unfortunately, will reflect poorly on the others. And the question is weighed by example, make sure they're dealt with and get rid of those. It's very simple. That's the culture and that has to be

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addressed. [LR283]

SENATOR HARMS: So are you going to make any effort...what I'm really driving at is what effort are you going to put in in regard to staff development because just changing and talking about change just sometimes doesn't go very well? So what are you going to do to help people understand how to do the very things you've said? Some people just don't know how to do it and... [LR283]

JOHN WYVILL: Well, we've had some informal dialogue with Nebraska Advocacy Services. We've had information dialogue with other organizations about how to enhance training. One of the things that we are looking at is how we can always improve our training in terms of the culture, in terms of our orientation process because if it is done correctly, those individuals should have those values that we endure in the orientation process. And with the help of the Legislature and the Governor, we are in the process of advertising I think four individuals that will be mentored, their sole job in experience with director care staff would be mentoring with the director care staff. In addition to one that is an orientation of facilitators to deal with the recruitment and retention to make sure that the employees are valued and stay to reduce the attrition rate. One thing that we're exploring statewide in Nebraska that we might use is take advantage of our technology to see if we can get nationally recognized experts in for training available either by teleconference. That's one of the things that came up yesterday. We were talking about west of Grand Island was a challenge. One of the things that we'll be looking at is how do we get the professional experts there beamed in to address those issues? So that's part of our ongoing progress and we certainly would welcome, as you hear the testimony for expertise of other individuals, other organizations, we have talked to some other organizations informally and said, nope, we're not going to touch that. Some very interested, just depends on the thing. But the biggest issue in terms of the training is the attitude of the individuals that you hire. And you know, as they say with Southwest Airlines and everything else is, you know, "attitude is everything. Just hire for attitude, train for skill, " and that's what we're doing. [LR283]

SENATOR HARMS: Well, I commend you for at least taking the steps because I think it's probably a move in the right direction. I think it's going to be a long trip. [LR283]

JOHN WYVILL: It's not going to be easy. [LR283]

SENATOR HARMS: No, and we're going to have to work to get there. Let's shift now, if I may... [LR283]

SENATOR LATHROP: Certainly. [LR283]

SENATOR HARMS: ...just for a few more minutes, please. Let's shift now to the

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community-based program. Okay? Where we're actually moving people from Beatrice to the community-based program. Do you really feel comfortable that we have right now today the right program established that we can provide the right services and support service for those clients to go there? And financially are we prepared to address that issue? [LR283]

JOHN WYVILL: I'd feel comfortable in terms of the placement because, in my conversations with the providers and others, it is also a courtship because not only do the guardians have a say in the placement, the provider has a choice as to whether or not. And the providers that I've talked to have said, if we're having conversations and you don't think that it's a match, then we don't want you to be putting a round peg into a square peg. And that's very critical because it's very critical you have the placement because if it doesn't work out, it's not fair to the provider, it's not fair to the client, and then we could have them right back where we are at BSDC and start all over again. You know, whether it would be perfect or not, it's trial and error, but the front end, I'm confident that we're doing everything that we can. Can we do better? Certainly. [LR283]

SENATOR HARMS: One of the things that the judgment brought out pretty clearly that we really lacked a lot of follow-up and communication in the length of communication and the length of coming back, and that's what bothers me a little bit. Hopefully you'll...I'm sure that you'll address this issue. But just by placing folks into a different environment, moving them from Beatrice, are we going to have the right follow? Are we going to have the right communication? Will the technology be able to handle this so you can communicate back and forth so that you truly are in control and you have visible what's happening to that client that you've just released? [LR283]

JOHN WYVILL: We have service coordinators that are in our DD system that work very closely in this transition process. Are there going to be glitches? There are going to be glitches. But just for a lot of our staff in terms of placing folks from BSDC is somewhat uncharted waters, and this is a learning experience for us and we have to make sure that we move carefully and cautiously to make that. You know, there's some people that think we're moving through fast; there's some, if you talk to the advocates, who think we're moving too slow. So... [LR283]

SENATOR HARMS: Well, I thank you very much for your comments. I think that the heart of this whole thing will lie, as I said yesterday, is that through the management of the Beatrice center because that's what this is all about. Regardless of what say or what we do, it all boils down to having the right people with the right education, like background, like training, that can manage this because we've placed our loved ones into that center expecting them to have the right care and be treated appropriately. And I think that's at least my goal and I'm sure this committee's goal to get us there. So (inaudible)... [LR283]

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JOHN WYVILL: That's what wakes me up at 3:00 in the morning is that responsibility. [LR283]

SENATOR HARMS: I can understand that. Thank you. [LR283]

SENATOR LATHROP: Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Yes, John. I heard you say you were closing two, you know, living units and they're going to be empty buildings. [LR283]

JOHN WYVILL: Yes. [LR283]

SENATOR WALLMAN: What will the state...are they willing to least that to private care providers or... [LR283]

JOHN WYVILL: We've had some informal conversations with some providers and provider networks and others to see if they're interested for using that. And it just in terms of long range plans, but one of the areas that we're going to be closing is the administrative building because they have some structural issues. So we'll be moving the folks in the administrative building, you know, that's not the same as the direct care staff. But they will be moving into the hospital wing sometime in the foreseeable future, and then we look at, we collapse and consolidate how to use that. So it is, you know, that's definitely things that we're talking about. [LR283]

SENATOR WALLMAN: And going a little further on, that Senator Harms's deal about education, you know, we heard yesterday, we're short of psychologist, psychiatrists. Now, do private care providers, are they short of those same individuals? [LR283]

JOHN WYVILL: I think they have different access to how they use them. So I don't know. I'm not familiar. I have not heard any shortages from them. But they have different arrangements. But I don't want to misspeak or mislead you. I just know about the shortage of our professional staff. They do it a little bit differently and they usually contract and stuff like that. [LR283]

SENATOR WALLMAN: Thank you, John. [LR283]

SENATOR LATHROP: Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. John, the longer I listen, the more confused I'm getting, (laughter) and... [LR283]

JOHN WYVILL: That's not what I want to hear, Senator. [LR283]

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SENATOR STUTHMAN: No, the issue that I have is, you know, we've got so many waiting for services, 1,500 or so, waiting for services. We've got the home, what we're trying to go from 300 to 200 and putting those people out in the community-based services, which would be taking the spot of 100 of those that are on the waiting list. And then we are closing homes at the Beatrice just because we moved these people out into the community base. And in order to attain the goal of minimum staffing ratio, we have to get the number of people, the patients, down at Beatrice. Okay. Is there any thought that you need more staff there that you could keep those people there or is the main objective to get these people out so the federal government doesn't have to pay as much in community-based services as they are in the institution? [LR283]

JOHN WYVILL: Okay. The twofold benefit, the number one is the right sizing is to address the staffing ratio. We may, from talking to my folks, we meet the minimum staffing ratio. To consolidate and close and reduce the number of patients there enhances that, and enhances and raises the bar. So instead of being in 26 living units, we are, I think, now in 23. If we collapse two more, that gives more coverage in terms of direct care staff, which translates to better enhanced care for our clients that choose to live at BSDC. So from that, we're talking about the whole ball of wax is that if we reduce the living units and reduce the census, we have better staffing patterns, we have more a better ratio, we have better active treatment, we have better...I think, that enhances the level of services for the families. They think we're doing good now. If we even have a smaller number, it's even better. The second issue to benefit is there are those individuals that can be better served in the community in terms of what community providers option. The sole purpose of an ICF/MR is temporary in nature in that their goal is to integrate into the community. It goes back to the question about the confusion about we're coming from two ways. We have...and Sandy is going to come up afterwards to say we have this pot of money right here that's for community-based services. That money is working for the waiting list. So money that is coming from BSDC is an oversimplification the money should follow the individual. So we have those individuals there coming into that. Will that have an impact on the waiting list? There's a possibility only because our number one priority in terms of the placement for our DD services coordination and make sure we find places for the BSDC residents. So there's multi-different levels for why we're doing what we're doing at BSDC that has an impact on everything. The uncertainty about, for example, Autism Center, about their contract, that has an impact on providers because you have 67 clients there. So it's all interconnected. [LR283]

SENATOR STUTHMAN: The funding source, John, for community-based services is a separate funding source. [LR283]

JOHN WYVILL: That's correct. And Sandy is going to come up hopefully remove that confusion for you. [LR283]

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SENATOR STUTHMAN: Okay. Thank you. [LR283]

JOHN WYVILL: Okay. Yes, Senator. [LR283]

SENATOR CORNETT: Yesterday when we were talking about staff retention and when we've been at the peak and the model that the other people looked at that we were doing things in regards to offering employees opportunities for further education, set so they could enhance their education and continue working at BSDC. And I asked the director--I can't think of his name right now--what are you doing? I know you're advertising for people all of the time and I know we're doing hiring bonuses now. What are we doing in regards for retention and education of staff that we currently have? Is the tuition reimbursement plan being utilized by staff? And are you working on promoting that? [LR283]

JOHN WYVILL: Senator, we are getting that information on the tuition reimbursements. I have not have that for you yet. But for the other questions for you is we're in the process of hiring four individuals that will be mentors with the money that has been provided by the Legislature. So they would work very closely with , not only the new staff...well, I stand corrected. I got the tuition...and I'll give that to you. [LR283]

SENATOR CORNETT: Okay. Great. Thank you very much. [LR283]

JOHN WYVILL: We're working with that in terms of working with mentoring with the direct care staff. We have a new orientation facilitator. We are working on several different things in terms of management by walking around. One of the frustrations that you will hear down the road in August I think when you talk about the employees is the frustration from some of the staff, as well as the leadership. And our CEO is making a point of visiting. We're doing a lot of the little things to make sure that the employee is being valued and treated as an equal. We've been having town hall meetings to make sure that they're being addressed. We most recently had one in May in conjunction with what the union's do it. We're working better culturally with them to make sure that we're addressing any employee concerns, whether it be a simple transfer issue or anything else that if it's an important enough for a union to do it or brought to the CEO or to myself, we make sure we address that and we try to address those issue. So we have several pieces of the puzzle that are working together, and I think I will like to think that with the union do it that we have a very positive relationship with them and an open dialogue with them. We may not agree with everything that they say and vice versa, but we both have the same thing at heart is that is what can we do to better enhance that because ultimately is that what Southwest Airlines has said: You take care of your employees and they'll take care of your customers. And our customers are our BSDC. So that's what we're doing in terms...that's just the numerous ones that we'll be addressing. [LR283]

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SENATOR CORNETT: Thank you very much. [LR283]

JOHN WYVILL: Okay. [LR283]

SENATOR LATHROP: John, I do have some questions precipitated by a lot of the discussion we've had this morning. And I want to clarify some things if I can. First, you have moved 26 people out--I'm trying to do the math--is that about right? You're from 308 down to 272 since the legislative session. [LR283]

JOHN WYVILL: We have two that have passed away. [LR283]

SENATOR LATHROP: Okay. So of the 26 that have brought you down to...am I doing the math right? [LR283]

JOHN WYVILL: Well, this is not the exact...this is not a good forum for me doing the math because of my stress level. So... [LR283]

SENATOR LATHROP: It's 36 it looks like. So you've had two folks pass away that would have brought you down to... [LR283]

JOHN WYVILL: In this year, So we went from 326 to 272, and we're projected to be at 267, I think, by the end of next week. [LR283]

SENATOR LATHROP: Okay. Let's take those numbers. I know that when we were bringing this up and when we talked about it in the Legislature we were in session and that was probably April, March, somewhere in that time frame and you were at 200 when you rolled out the plan to go from 308 down to 200 roughly. And you're now at 272. How many of those people have gone to a community-based program? And how many of them have actually gone to a nursing home? [LR283]

JOHN WYVILL: Okay. I can get that number for you because we track that and have that out... [LR283]

SENATOR LATHROP: I would imagine you can have an idea what it is. Can you share that with me this morning? [LR283]

JOHN WYVILL: I would say early on the majority of them have gone to nursing facilities and then more recently we're now getting them into community DD providers. And that is more the nature of the beast in terms of it takes about a month, month and a half working with a community provider, a nursing facility could be... [LR283]

SENATOR LATHROP: Okay. So of the 34 since we've gone from 308 down to 272, two

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people passed away, how many of the remaining 34 roughly went to nursing homes?
[LR283]

JOHN WYVILL: Senator, I would feel much more comfortable just to give you a list that you can have the actual list in front of you. But... [LR283]

SENATOR LATHROP: Is it more than half? [LR283]

JOHN WYVILL: No. I don't think so. [LR283]

SENATOR LATHROP: Okay. [LR283]

JOHN WYVILL: But I don't want to mislead you. [LR283]

SENATOR LATHROP: But when we talk about moving people from Beatrice to community-based care, in reality a number of these people simply went to nursing homes. [LR283]

JOHN WYVILL: The guardians had requested nursing facilities, yes. [LR283]

SENATOR LATHROP: Yesterday, the last slide that you put in your presentation showed that we have ICF/MRs, we actually have the Beatrice State Development Center is and ICF/MR. [LR283]

JOHN WYVILL: Um-hum. [LR283]

SENATOR LATHROP: But we also have Mosaic providing or serving in the capacity of an ICF/MR in Axtell, Beatrice, and Tri-City. Is that true? [LR283]

JOHN WYVILL: That's correct. [LR283]

SENATOR LATHROP: And you have today two or three times said the purpose of an ICF/MR is a temporary stay. [LR283]

JOHN WYVILL: Um-hum. [LR283]

SENATOR LATHROP: And I want to make sure that before we accept that as the landscape, as you this, the Mosaic in Axtell, which is an ICF/MR has 108; in Beatrice there's 127; and in the Tri-City region there's 9. Are you doing anything to move those people out of Mosaic or are you satisfied with their placement? [LR283]

JOHN WYVILL: We're not doing anything with the private or on ICF/MR. [LR283]

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SENATOR LATHROP: So the purpose of the ICF/MR isn't necessarily a temporary stay because you're satisfied with the placement at the Mosaic, but you've described Beatrice and said it's an ICF/MR and the purpose is a temporary stay. And you're introducing, I think, into our conversation an assumption that Beatrice has not place except for a temporary stop in the developmental disability care. And I don't want to argue about whether that's true or not true, except to point out that in Mosaic, who's providing ICF/MR services, we're okay with them staying there. And what you're trying to do is reduce the census or the population of Beatrice, which happens to be an ICF/MR. Do you see the point I'm making? [LR283]

JOHN WYVILL: I know the point you're making. I would just say that we can certainly share with you the regulations really pertaining to ICF/MRs and let you draw your own conclusions about...it's more of a transitional nature. It's not a final resting. [LR283]

SENATOR LATHROP: Ultimately, don't you agree that as we search for a solution, we're going to have to define what the purpose and what the services are that Beatrice should provide? [LR283]

JOHN WYVILL: Correct. [LR283]

SENATOR LATHROP: And whether that turns into temporary only, like the ITS program, or something broader than that we'll have to up. [LR283]

JOHN WYVILL: That's correct. [LR283]

SENATOR LATHROP: And Ron Stegemann, who was here yesterday, suggested that there are some people who will not, because of their risk to themselves or the community, wouldn't be a good placement in a community setting. [LR283]

JOHN WYVILL: Right now, that's absolutely correct, Senator. [LR283]

SENATOR LATHROP: All right. And so it may be that Beatrice turns out to be the right place and the right facility for us to provide placement of individuals who cannot safely be placed into a community setting... [LR283]

JOHN WYVILL: That's absolutely correct. [LR283]

SENATOR LATHROP: Okay. Did I hear you say in answer to Senator Wallman question that you are exploring the possibility of having a private contractor come in and take over one of the cottages at Beatrice and provide community-based care from that facility? [LR283]

JOHN WYVILL: An empty, empty building. That might be a possibility. [LR283]

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SENATOR LATHROP: What is it that a...there's something about that that troubles me. If we're going to take a cottage, empty it out in the plan that you've outlined for Senator Harms, if we reduce the population and now have four empty buildings at Beatrice, are we not just privatizing Beatrice? If we turn those cottages over to a contract provider, have we done anything more than simply...I mean, it's the same campus, it's the same facility, they're going to go to lunch at the same place and get their care from the same place. Aren't we just moving towards...is that just sort of a left-handed way of privatizing Beatrice? [LR283]

JOHN WYVILL: No, not necessarily, Senator. I think we are certainly open to any users of the facility if they have...as we have our buildings become vacant. One option is the possibility of a community providers interested in running a group home, which is not to be confused with an ICF/MR license. A group home separate from there on the campus, we will certainly be definitely talking to them. So it's not a question of privatizing. It would be a question of we have empty vacant space. Somebody come forward and say, we want to rent your space to do X, Y, and Z, and then we go through the appropriate procurement process and lease it and all that kind of stuff. [LR283]

SENATOR LATHROP: When people go into a private community-based program...not a private, but at community-based program, is the habilitation there that we find at Beatrice? [LR283]

JOHN WYVILL: In terms of the same level? [LR283]

SENATOR LATHROP: Yeah. If someone is at Beatrice...we heard yesterday, they have a constitutional right to habilitation. And the habilitation would be to improve their function, both in terms of activity, of daily living, being able to groom themselves, the basic needs to improve those and their skills. But it's also vocational and those sorts of things. Once we move them from that environment to a community-based program, do they get the same level of habilitation? [LR283]

JOHN WYVILL: I'm not sure how to answer that question, Senator. I think that--and I'm not trying to dodge it--it think when you have a state run facility and when you have a responsibility and an mandate about the U.S. Constitution, federal laws and all that, our rights, duties, and responsibilities to those individuals flow through there, which is a constitutionally protected right. And we are responsible for those individuals. That impose a certain requirements us. That is a separate duty then in the community because our relationship to them is governed by contrast. And then any other issues without getting into a lengthy legal discussion. It might be an apples and oranges comparison, but they're getting similar services. [LR283]

SENATOR LATHROP: So the constitutional duty that Mr. Mason talked about and Ms.

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Fenner talked about, that arises from the fact that their liberties are restricted with a placement at Beatrice, and you don't believe a similar level of constitutional concern is present with a community-based placement. [LR283]

JOHN WYVILL: I don't think so. I'd have to defer to the legal counsel because... [LR283]

SENATOR LATHROP: And as a consequence, the duty to habilitate is not there necessarily as it would be with a placement at Beatrice. [LR283]

JOHN WYVILL: I believe so. [LR283]

SENATOR LATHROP: All right. Those are the questions I had. Anyone else? Senator Cornett. [LR283]

SENATOR CORNETT: That brings what, the questions that Senator Lathrop is asking, brings back a term that was brought up yesterday, "minimally acceptable" for care or rehabilitation. When Mr. Mason was discussing the level of care that was the minimum required, would the private providers have to meet that standard? [LR283]

JOHN WYVILL: The providers have to meet the standards set forth in their contract, and I think... [LR283]

SENATOR CORNETT: And that would be set forth in the contract. [LR283]

JOHN WYVILL: In the contract and also they...I think I will start in the discussions in July when you hear testimony from the various regulatory oversight, and we have contract oversight. In that contract oversight, we ask the providers to assume certain duties and set the federal regulations required. [LR283]

SENATOR CORNETT: My point is I believe that it was testified to yesterday that we are currently at minimally accepted practices. I mean, what is the very...we just meet that. If these private providers are to provide the most services that we currently are offering in regards to habilitation, are we going to meet that, will they be able to meet that standard? [LR283]

JOHN WYVILL: My hesitation in answering your question is the ICF/MR that are governed by different regulations than the providers, and I think what would be beneficial for the committee would be the different roles and responsibilities that come forward. There are certain things that providers are required to do that are very similar, but there might be different congressional or different authority. [LR283]

SENATOR CORNETT: So if they are in a state facility, the requirements are different than if we place them in community-based service. The standard of... [LR283]

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JOHN WYVILL: They're similar but different. Similar, similar responsibilities, but I think different...I'm not answering your question well. I'm trying to wrestle with it. [LR283]

SENATOR CORNETT: My question is are they...when you said that they may not receive the same level of habilitation if we outsource to community-based programs, is there a different standard of habilitation in community-based than there is for a state facility, and will they still be receiving the minimum care needed? And is minimum even the standard that we should be looking at? [LR283]

JOHN WYVILL: Okay. I think there's two issues. If you talk to the parents and families of BSDC, they will tell you that the community providers do not have the same regulatory oversight and purview at BSDC; that we have CMS, DOJ, Nebraska Advocacy Services. Nebraska Advocacy Services does it on campus by federal law and access agreement. CMS is there because we accept federal money and they come in through the ICF/MR department. Then we have Department of Justice that has a different congressional authority that comes in there. Community-based providers, we have oversight over them for the same protection from harm and other duties. We have, by our contract, ability to enforce the contract. We have regulatory and licensing, and then we have the federal oversight. So it's a little bit different. Same thing to make sure that they provide the services of active treatment and all that kind of stuff, as well as protection from harm, and to ensure that they do things, but it's a little bit different. Hopefully, I'm explaining it. [LR283]

SENATOR CORNETT: This will be...put you in an awkward position. [LR283]

JOHN WYVILL: Yeah. [LR283]

SENATOR CORNETT: Do you feel that they have less oversight than you have at BSDC, the private providers? [LR283]

JOHN WYVILL: Private providers are not much in the press as BSDC, but I think the oversight is similar. [LR283]

SENATOR CORNETT: Are the remedies the same? We are here currently because of the Department of Justice findings that BSDC is out of compliance and... [LR283]

JOHN WYVILL: Uh-huh. [LR283]

SENATOR CORNETT: ...the clients haven't necessarily received the care that they should have received. What are the guarantees that if we put them in community-based service, where is that oversight going to be and who is going to step in if there's a problem? [LR283]

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JOHN WYVILL: Okay. I think the oversight is what I said about the contract oversight. If there's a complaint, there's adult protective services that comes in, works closely with regulatory and licensing. You have regulatory and licensing. You also have our certification process which is reviewed. [LR283]

SENATOR CORNETT: Will inspectors going in the private facilities like they do at BSDC? [LR283]

JOHN WYVILL: They don't come out with as much frequency. They either come in either through our certification process or in response to a complaint that we send out, adult protective services. To my knowledge, providers don't have the federal inspectors out there as much as we do, and there's always that potential. [LR283]

SENATOR CORNETT: So the state will basically be acting as the Department of Justice is now in the private providers is going in and inspecting the people that they have contracts with? [LR283]

JOHN WYVILL: We do that now. [LR283]

SENATOR CORNETT: You do that now. [LR283]

JOHN WYVILL: Yeah. And I think these are good questions. I think regulation and licensing with Helen Meeks and others, I think the regulatory scheme for community providers and for the ICF/MRs is a topic that will be up in July that will...a lot of those questions I believe will be answered so you can decide whether or not that's appropriate or we need to make enhanced changes in community-based care. [LR283]

SENATOR CORNETT: I don't want to see us moving people to community-based care and having less oversight when we already have the problems that we have now with the level of oversight we have now. [LR283]

JOHN WYVILL: Uh-huh. Yeah, I think... [LR283]

SENATOR LATHROP: That is a topic that we have on the agenda for July. [LR283]

JOHN WYVILL: Yeah. [LR283]

SENATOR CORNETT: Yes. [LR283]

JOHN WYVILL: Yeah, I think community providers can give you their perspective. The community providers will probably think that we have too much oversight. If you ask the parents and families, it's not enough oversight. And it's just a question of...there was a

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law that was introduced in Missouri in which they asked for regulatory oversight. Some providers have said that if we wanted the scrutiny that you guys would, we would be out of business, and in terms of the scrutiny. I'm not making that as a statement. I'm just saying what I've heard. [LR283]

SENATOR CORNETT: Okay. Thank you. [LR283]

SENATOR LATHROP: That's a little disconcerting if they're concerned about not being able to meet the standards that the ICF/MRs are held to, but... [LR283]

JOHN WYVILL: Well, they said that if they had the level of scrutiny that we had. [LR283]

SENATOR LATHROP: Yeah. Okay. I think that...anyone else have any questions? All right. We thought it would be ten minutes, John, and...but I think it's been very, very helpful... [LR283]

JOHN WYVILL: Well, thank you, Senator. [LR283]

SENATOR LATHROP: ...and you answered an awful lot of questions and gave us more information. [LR283]

JOHN WYVILL: Okay. I'll be back. [LR283]

SENATOR LATHROP: Thanks. I think that brings us to Sandy Sostad, who would be anxious to... [LR283]

SANDY SOSTAD: Anxious, yeah. [LR283]

SENATOR LATHROP: ...anxious to speak publicly on the issue of finance. [LR283]

SANDY SOSTAD: Oh yes, I love public speaking. [LR283]

SENATOR LATHROP: Just so that the record reflects what we have going on here, it turned into a panel and that's sometimes difficult to keep a clear record and an accurate record of who is speaking and who is saying what. So what we'll do is...are we going to have you start out, Sandy? Is that the...that's the strategy? [LR283]

SANDY SOSTAD: Yes. [LR283]

SENATOR LATHROP: Why don't we have each of you identify yourselves, and then we'll start out with Sandy. And then if you can just kind of observe this as a matter of keeping a clear record, if we can just have Sandy talk. And then are the rest of you here to answer questions? And then they are shaking their head yes, which is also hard to

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get on the record unless I say that. So what we'll do is we'll have you identify yourselves, we'll have Sandy do her presentation, and then we'll go to sort of a question and answer. Okay. [LR283]

SANDY SOSTAD: Okay, for the record, my name is Sandy Sostad, it's S-o-s-t-a-d. I work in the Legislative Fiscal Office. I've probably worked in this area for 25 to 30 years, so I have some experience with it. And the people that are up here with me have, on this side of the table, similar kinds of experience--Vivianne, of course, is new to the system--and I'll let them each introduce themselves now and what they do. [LR283]

SENATOR LATHROP: Okay. [LR283]

VIVIANNE CHAUMONT: Vivianne Chaumont, V-i-v-i-a-n-n-e C-h-a-u-m-o-n-t, I'm director, Division of Medicaid and Long-Term Care. [LR283]

WILLARD BOUWENS: Willard Bouwens, B-o-u-w-e-n-s, and I'm the finance administrator for the Department of Health and Human Services. [LR283]

DON SEVERANCE: And I'm Don Severance, S-e-v-e-r-a-n-c-e, and I work in Division of Developmental Disabilities as a disability services coordinator. [LR283]

SENATOR LATHROP: One thing I'll say is that we had some concern from folks who were in attendance yesterday that they couldn't hear very well, so try to keep the mike in front of you and try to speak up loud enough so that we can all hear you and everybody in back has the benefit of your testimony. [LR283]

SANDY SOSTAD: (Exhibit 2) Okay. I think what we'll do is we'll just reiterate initially what was presented yesterday. We thought it was important to give you a snapshot of how much funding is out there right now for developmental disabilities, and if you go to that handout, I think it was on your desk, there's a small, little, 35-page handout that we're just going to whip right through here, so...(laugh). [LR283]

SENATOR LATHROP: And maybe, so that we...Sandy, if I can interrupt you. [LR283]

SANDY SOSTAD: Uh-huh. [LR283]

SENATOR LATHROP: The handout you're talking about is entitled "Department of Health and Human Services Developmental Disability Funding 2006-2007." [LR283]

SANDY SOSTAD: Yeah. And the first page after the initial page, so it would be the second page, they're numbered down in the corner for your reference, this is what was presented yesterday and the pie charts that followed, just to give you the perspective. We've got \$274 million that's going out of the Department of Health and Human

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Services in terms of total funding for developmental disabilities. As you can see, General, cash, and federal sources. You see BSDC in the first column there to the left (sic). We've got roughly \$50 million; again, 772 clients; 700 FTE are funded there. You get to... [LR283]

SENATOR LATHROP: I'm going to...and maybe, so that we...Sandy, if I can interrupt you. [LR283]

SANDY SOSTAD: Okay. [LR283]

SENATOR LATHROP: I think you're trying to hurry through this and you really don't need to. I'd like you to kind of walk us through this because this seems to be where we summarize all the information. If you can, just tell us what the columns and the rows are so that we can follow. [LR283]

SANDY SOSTAD: Okay, you will see across the top, this is the service, okay: Beatrice, the private ICF/MRs, developmental disability service coordination, developmental disability administration, and then the three columns that follow are the community-based services that we have that I will call aid to developmental disability programs. They are found in Program 424 in the state budget, and then the Medicaid part is in Program 348. So then you'll see the sources of funding--the General, the cash, and the federal; and then the total funding to give you a perspective on that. So we'll talk about Beatrice in the next section. We have a whole section on Beatrice we're going to talk about. The private ICF/MRs, again, that's Mosaic. For the old-timers, that was Bethphage and Martin Luther years ago. They merged; they became Mosaic, so that's what we have. Private ICF/MR: 246 clients is what they testified yesterday. DD service coordination: you can see \$10 million, roughly, spent there, we have a breakdown of that later on in the handout, but we've got 222 people that work out in five regions of the state that provide service coordination and they are funded with state funds and federal Medicaid match. The DD administration, that would be 15 people there. That would be John's shop, the people that work in the central office here in HHS that work with developmental disabilities administration. And then the community-based programs, the aid that goes out, and you'll see the total funding there, and we will have a section that will talk about that later on in the presentation. So \$274 million total through HHS. Now this does not include, we have community-based providers, we the private ICF/MRs, they have other sources of funds. They have Social Security income from clients. They have client fees. The privates probably have some funds, private funds, that they get, so this is not all encompassing. There are some other resources for other providers that are not shown here. These are just the resources that come through the Department of Health and Human Services. When you look at the total and you compare it to the General Fund budget of the state, this is about 3.67 percent of our General Fund appropriation for 2006-2007, so roughly 4 percent of the General Fund budget is encompassed in what you're going to look at today. The next two handouts were what

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John, again, had yesterday and the first one talks a little bit about, well, where are the funds in terms of what services: 52 percent, the majority of the funds in this system, go out, like we said, to the community-based DD services--52 percent are General and federal funds that serve clients; 18 percent of the total funds go to Beatrice; 12 percent of the total funds come through Medicaid--that would be paying for medical services for clients that are out in the community-based programs; Mosaic gets roughly 7 percent of the funds, and another 7 percent of the funds is state only--these are clients that are out in the DD programs but are not Medicaid eligible so they get state funding for them; service coordination, about 4 percent of the total; and DD administration less than 1 percent. And then the final chart that was presented yesterday just shows your total overall funding in this area. Most of it is federal, 55 percent federal, 42 percent General Funds, and 3 percent cash funds. Cash funds, again, can come from tobacco settlement funds, client fees, that kind of thing. Clients pay based upon an ability to pay in these programs. So that's a quick overview of the funding. The next two sections...if you have any questions, we can answer those. The next two sections we'll talk a little bit about Beatrice and then we'll talk about community-based programs in the next section, so... [LR283]

SENATOR LATHROP: All right, let's see if anybody has any questions at this point. Nope, I think we're all following you. Thanks. [LR283]

SANDY SOSTAD: Okay. If you go to the next section, it is entitled "Beatrice State Developmental Center," and then we have a couple charts on DD service coordination and DD administration. The first chart there actually shows some of the census data for Beatrice. This information has been gathered by our office from the agency over a long period of time and we've put it what we call the "Legislator's Guide" and we distribute it to senators. So that is the source of the information. It was provided by the agency. I would say that the one thing that I did change here is when you look at FTEs, the FTEs are always sort of, I think from the perspective of the agency, what's budgeted for. The remaining, let's see, six years or so, beginning in 2000-2001, those represent filled FTEs. The ones above that point in time I would say are probably budgeted FTEs. But for the last six or seven years there we have filled FTEs. What I would say on this, if you look back in history, in 1966 there were probably 2,300 or more clients at Beatrice. When we started doing the consent, the class action suit in 1972, there were 1,347 clients in Beatrice. The beginning of the chart that I show here, in '75-76, when we actually began the plan of implementation to actually move through the consent decree and that, we're down to 990. And originally, I think, in the...when they were looking at that deinstitutionalizing back in the seventies, their goal was to get down to 250 people and they never did. If you look around '85-86, when they stopped the consent decree, it was over after ten years, there were around 450 people at that time. So since that point in time, not a lot of change in terms of the average daily census. What you'll see around, I think it's, '95-96, you'll start to see an increase in admissions, increase in discharges. That's when they put in the outreach treatment service where they come in for a three

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months' stay and then they leave service. So that accounts for why you'll see an increase in admissions and discharges there. That's about all I have on that. Okay? When we go to the next chart, BSDC, this is just historical expenditures. Again, we're showing you the source of funding, we're showing you the average daily census, we're showing the ending census, the average cost per client. It's over a 33-year period. Basically, when the Legislature funds Beatrice, the way that we look at it is they submit a budget request and we review the cash that's available for Beatrice and we review the federal funds that are available for Beatrice, federal funds, again, primarily Medicaid. And we'll look at the cash flow and we'll say, we're going to maximize those sources of funds so we say we think they're going to have so much cash, we think they're going to have so much federal, and then we carry over a certain amount each year so that they have a cushion for the next year. So the remainder of their budget then is General Funds and their budget goes up every year based upon state salary increases, the fixed costs of institutions. The Legislature has typically always put in additional funding for food, medical services, utilities. That's a fixed cost for those institutions and we call them unique costs of institutions, and the Legislature has pretty much generally funded those increases year by year, so... [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: The amount in per client cost has risen dramatically,... [LR283]

SANDY SOSTAD: Right. [LR283]

SENATOR CORNETT: ...more so than the reasons you just explained. [LR283]

SANDY SOSTAD: Uh-huh. [LR283]

SENATOR CORNETT: And I'm making an assumption here. I'm assuming as we reduce the census at BSDC that the people that need less services have been moved out to the community and the cost per client has increased because the people that need the most services remain. [LR283]

SANDY SOSTAD: Right. I had a few...there's actually a chart on the next page if you want to look at average cost per client. There are a few things, if you compared '05-06, roughly \$123,000 there, average cost per client. With the CPI it would be about \$42,000. So why is there a lot of difference? I mean, I had a few thoughts on that. I thought maybe some of it is there's a fixed cost to the institution. We've got a big campus there. We've got a lot of buildings, we've got a lot of fixed costs, so that's one thing. Secondly, there's...if you look at the next chart, 75 percent of the costs of Beatrice are in salaries and benefits, so the state has periodically increased the salaries of all the...and the benefits of the employees down there. That's another reason the cost is increasing as it is. Thirdly, what you talked about a little while ago, there's federal

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requirements for certification. You've got to meet the ICF/MR staffing requirements, the medical requirements, and I think that's a big part of it. It's more, in my mind, I'm not a program, it's more of a medical model. You've got a lot of medical staff there and you've got a higher cost and you've got to meet staffing requirements and that kind of thing. [LR283]

SENATOR LATHROP: We also see, if I can, on page 6 that you showed us, the percent of severe and profound clients is... [LR283]

SANDY SOSTAD: Right. [LR283]

SENATOR LATHROP: ...is significant. [LR283]

SANDY SOSTAD: That was my fourth thing, the type of client that we're serving, severe and profound types of clients there. And again, like I said, it's more of a medical model, an ICF/MR model, that they have to comply with those requirements. So that's why I think that the average cost is going up much higher, much...is much higher than what the rate of inflation is. Those are some things that I thought. I don't know if anyone else has anything to add but... [LR283]

SENATOR LATHROP: The panel is shaking their head no. [LR283]

SANDY SOSTAD: They're shaking their head. [LR283]

SENATOR LATHROP: Okay. [LR283]

SANDY SOSTAD: Okay. Thanks, panel. (Laugh) [LR283]

WILLARD BOUWENS: Did a good job. [LR283]

SANDY SOSTAD: The next, the next chart, just to give you a perspective on what we look at when we're budgeting for the institution, you can see the breakout of salaries, and I tried to breakout salaries because you talked a little bit about that. That's sort of an issue. So you can see on the left-hand side, I'm on page 9 now, the total salaries permanent, temporary, overtime, premium pay, shift differential, comp time, and other personal services, and then benefits, and total salaries. The one thing we have to look at, too, when we're looking at salaries is down under operating expenses. Sometimes they stick some contractual salaries down there and you'll see that pop up. In the current year, '07-08, under operating we've got about \$144,000 being spent for contractual. That's to get those people into the institution right now to solve some of their problems. So they're contracting for people. I guess the point I wanted to make on this is if you flip to the next page, this is percentage of total. So this is the sheet that I just showed you here. And if you go to the next page, percent of the total, you can see

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that if you look under overtime, which is the third line down, back in fiscal year '98 overtime was about 2 percent of the budget. If you look in the current year it's about 7.8 percent of the budget. So you do see that we have some growth in the overtime. [LR283]

SENATOR LATHROP: Can I ask two questions on the overtime? [LR283]

SANDY SOSTAD: Uh-huh. [LR283]

SENATOR LATHROP: On page 9 you have overtime listed. You've not attempted in this chart on page 9 to identify mandatory versus voluntary overtime. [LR283]

SANDY SOSTAD: No. No. [LR283]

SENATOR LATHROP: It's all overtime. [LR283]

SANDY SOSTAD: All overtime. [LR283]

SENATOR LATHROP: And the second question I have is, is the overtime number the time and a half, or is it just the premium for the overtime? [LR283]

SANDY SOSTAD: I don't know. I'll defer to Willard. [LR283]

WILLARD BOUWENS: Yeah, it's time and a half, most generally, it's time and a half, recognizing that we have 24-hour, 7-day operation facilities. Then you have holiday pay. Sometimes that gets higher than that. I'm not an HR expert but I know that it's at least time and a half. [LR283]

SENATOR LATHROP: But the line for overtime, if we paid an employee \$10 an hour and that showed up on just salaries, \$10 an hour, and then the person worked an hour of overtime, first he gets the \$10, then he gets \$5 more, does our overtime line have just the premium, or the \$5, or does it have the whole \$15? [LR283]

WILLARD BOUWENS: It just has the overtime amount, because they're... [LR283]

SENATOR LATHROP: So it's the premium. It's... [LR283]

WILLARD BOUWENS: Correct. [LR283]

SENATOR LATHROP: That's how much we pay over and above what we're paying... [LR283]

WILLARD BOUWENS: Right. [LR283]

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SENATOR LATHROP: ...for the base salary. [LR283]

WILLARD BOUWENS: Correct. [LR283]

SENATOR LATHROP: Okay. [LR283]

WILLARD BOUWENS: Their base salary is in the top line and the overtime would be the additional. [LR283]

SENATOR LATHROP: Okay. [LR283]

WILLARD BOUWENS: That's correct. [LR283]

SENATOR LATHROP: Thank you. [LR283]

SANDY SOSTAD: Okay. Again, on page 10, you can see that over time at Beatrice, total personal services, which is sort of in the middle of the page there, in fiscal year '98 it was about 75 percent of the total, and through the current year it's about 75 percent. So salaries and benefits are about the same percentage, but you'll see that benefits have actually gotten to be grown much more than salaries over time and that's just in general for state employees that you would see that kind of trend, I would think, if you'd look at any agency. Let's see, the thing that, you know, is a concern, I suppose, from a fiscal point of view is as we move clients out of Beatrice our revenues are going to go down. We have cash and federal revenues that come based upon the number of clients that we have, so as we start to move those clients out of Beatrice and the money follows the client out into the community, I have somewhat of a worry what the impact is going to be on the General Fund in the next couple years in terms of maintaining what we still have at Beatrice. So that's something that on the Appropriations Committee we're going to have to look at, because we're going to lose a lot of our cash and federal revenue as those clients leave, and some of the General Fund revenue that will go with them, so.... The next chart, page 11, it's just, for me, it was a snapshot view of another way you could look at Beatrice if you have any inclination to do so. We're looking at fiscal year '03 compared with fiscal year '07, actual expenditures. This is the way they budget, by subprogram. So if you have an interest in looking at how are the subprograms laid out, what do we spend for pharmacy, you can look down there and that will give you an idea of what pharmacy is. I thought we might see more changes in the percentage of total. If you go to the far right-hand side, I thought we might see more changes in terms of maybe pharmacy being a bigger component or psychology or some of those kinds of things. But I didn't see much movement in terms of percentage of total over the four-year period. Possibly if we looked at a longer period of time, we would see more change. What you did see at the top is the unit, the ICF/MR units, as percentage of total changed a little bit. What I'm guessing is maybe it was a coding there. Overall,

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percentage of total in terms of the care in the units was about 43 percent in the initial year, fiscal year '03, and was about 41 percent in '07. So if you added them all together...so it didn't change overall but possibly within the units they did some changing in the accounting. I don't know if you have any questions there. [LR283]

SENATOR LATHROP: Senator Harms. [LR283]

SENATOR HARMS: Sandy, when we look at the psychology services and pharmacy, when you go back and look at the federal findings, they're definitely short in providing the right kind of services there, as well as even pharmacy. I would anticipate this cost to go up. I think once John...he's able to implement what he's previously testified, I would say this is going to change a lot because they have a shortage there and don't have the right services available at that point. So I'm assuming that's part of the problem here. [LR283]

SANDY SOSTAD: Uh-huh. [LR283]

SENATOR HARMS: Pretty much points it out when you see the percent. It should be much higher in that kind of facility and services. [LR283]

SANDY SOSTAD: Right. [LR283]

SENATOR HARMS: The other thing I wanted to ask you in regard to salaries that we were looking at, with the shortages that we have and probably the issue of hiring the appropriate people with the right kind of educational degrees and to slowly change the culture of that organization, when I had a discussion with you, I think right near the end of the legislative session, I asked you about the funding aspect of this and you felt like we at least had the adequate funding and funding shouldn't be an issue at that point in regard to trying to straighten some of this up. Is that still where you're thinking we are? [LR283]

SANDY SOSTAD: I think...this is my perception. [LR283]

SENATOR HARMS: I'm putting you in an uncomfortable position here, but... [LR283]

SANDY SOSTAD: I think the funding is adequate right now, but how it shakes out in terms of the next biennium I'm not sure, in terms of when we lose revenues, in terms of what staffing they finally end up at and how much that's going to cost in terms of General Fund dollars. I'm not sure I could answer that. Possibly, do you have any perception? [LR283]

WILLARD BOUWENS: Senator, it's just as Sandy said. What we'll do as we're in the process now of preparing our 2009-11 budget request, we're working on that now,

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Sandy indicated earlier, our job is to estimate revenue sources that we will get from other payers, such as Medicare, Medicaid, private individuals and so forth, and then whatever is left becomes a General Fund support. I think what is important to remember, all the clients, I think with 99.9 percent determination, are Medicaid eligible that come into Beatrice. So any client or any expense that comes from Beatrice is funded with support from the federal government and today it's at about 60 percent. So any of the clients that come in or any of the expenditures that we have that are appropriate for the care of those clients (inaudible) will receive the federal share of the dollars. But we will be doing those estimates to determine what our revenue sources are and what the request would need to be for the remainder of the funding of that program. [LR283]

SENATOR HARMS: As we...as you prepare your budget for the Appropriations Committee next year, there was a lot of discussion, at least on my part, in regard to the Appropriations Committee about benchmarking and about being able to determine how we compare with other states, other organizations like Beatrice. Are you moving at all in that direction so that when we are able to look at...we're trying to find a way to provide services but, yet, in the most cost-effective manner possible. And had this discussion more than once, both on the floor and both in the Appropriations Committee, in regard to the benchmarking and (inaudible) so that we can have some way to compare what's it's costing us and whether or not we're moving in the right direction and whether we truly are cost-effective based on the FTE production here. [LR283]

WILLARD BOUWENS: Can you speak to the benchmarking? I'm not real familiar with the benchmarking. I do remember that discussion going on. But just briefly what the...the way the department approaches the budget request for Beatrice will be dependent upon that notebook you have in front of you there from DOJ that says what is the appropriate staffing level. So we first determine the appropriate staffing levels, the program does that, and then we fund those and then we fund the fixed costs that go with that. So our goal would be to only request the funds that are necessary to meet all the certification requirements and to maintain the safety and the quality of care for the clients at Beatrice. [LR283]

SENATOR HARMS: What I'm trying to come to grips with, I mean there are other ways you can do that and sometimes looking at that versus efficiency and still providing quality of care is important for us. And I know that there are, at least, national organization you can go to that you can get those benchmarks. And so that's why I'm asking the question, because that question, if I'm on Appropriations Committee next year, which I don't know about, I'm definitely going to go after that issue because I think it's very important for us to have some idea to see where the efficiency is, and that it is available. That's all I'm asking, to see whether or not you're on target (inaudible). [LR283]

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WILLARD BOUWENS: And, Senator, Direct Wyvill and them may have already been doing that. I'm just not familiar with that. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: When we toured Beatrice and we spoke with the director, he said that the Department of Justice said the number of employees we should have working there, and I can't remember that exact number, I'd have to look at my file folder, versus the number of employees we actually currently had working there, are we fully funded; is it budgeted currently in Beatrice to hire everyone that is needed? If we could hire everyone tomorrow, is there money in the budget to fully fund Beatrice at the level? [LR283]

WILLARD BOUWENS: I'm not, Senator, I'm not familiar with what that level is. I haven't...I mean, we're in our second...we're going to just start our second year of our biennium and we have a funding level that was provided to us by the Legislature and it was at a certain level. I think Sandy shared some of those numbers with you. [LR283]

SENATOR CORNETT: Yes, but are...those numbers,... [LR283]

WILLARD BOUWENS: But I don't... [LR283]

SENATOR CORNETT: ...are the full numbers we need to reach... [LR283]

WILLARD BOUWENS: I cannot answer that question. I don't know for sure because I have not seen what the level of staffing that we are required to have, I haven't seen those numbers. [LR283]

SENATOR CORNETT: Because whether...I'm trying to get to the point that was made to me that they didn't...that people did not believe that the budget was fully funded to be able to hire. If we could hire everyone we needed tomorrow to reach those levels, the money was not there to do that. [LR283]

WILLARD BOUWENS: And the way I would answer that for you, in our past the way we funded the facility at Beatrice, because of the turnover rate of...I don't know if it's still 30 percent, it used to be 30 percent of our staff would turn over in a year, while we would set a level of funding for that expectation of turnover because it has historically always stayed the same, so if that 30 percent turnover did stop we would not have enough funding to fund all of those people for 12 months in a year. That would be correct. [LR283]

SENATOR CORNETT: So if we were able to hire everyone that was needed to be hired... [LR283]

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WILLARD BOUWENS: And we had no turnover. [LR283]

SENATOR CORNETT: ...and we did not have the turnover, which you're going to have turnover in any job but if you were able to keep those positions full, be at full staffing or close to full staffing, the question is, are we budgeted for that? [LR283]

WILLARD BOUWENS: I would say we would not be at this time. But as we do our '09-11 budget, as they determine the appropriate level of clients at the facility and the staffing needs, that's where we'll be making that adjustment. [LR283]

SENATOR CORNETT: So with all of the advertising for jobs that we have going on, if we were able to fill those positions, where would that money come from? [LR283]

WILLARD BOUWENS: We wouldn't currently have it in our budget. [LR283]

SANDY SOSTAD: The Legislature did authorize (inaudible) was it a million? [LR283]

WILLARD BOUWENS: We have \$1.5 million that the Legislature authorized for that retention, recruitment, I think for those...maybe those four positions that John was talking... [LR283]

SENATOR CORNETT: Right, but that's retention and recruitment. [LR283]

WILLARD BOUWENS: ...but that's...that's... [LR283]

SANDY SOSTAD: Yeah. [LR283]

SENATOR CORNETT: That's not actual salaries then. [LR283]

WILLARD BOUWENS: ...down the road. That's correct. [LR283]

SENATOR CORNETT: The next question is, I know that businesswise a certain amount of overtime is beneficial rather than hiring more employees, because you have benefits. At what percentage does the overtime cost more than hiring more employees would? [LR283]

WILLARD BOUWENS: I don't know the answer to that, Senator. [LR283]

SENATOR LATHROP: And just so the record reflects this, and this isn't...you all shook your head no, so we got a negative response from our distinguished panel. [LR283]

WILLARD BOUWENS: If you would like us to get that for you, we can do that. [LR283]

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SENATOR CORNETT: I would appreciate that. [LR283]

WILLARD BOUWENS: Okay. [LR283]

SENATOR CORNETT: Because the amount that we're spending on overtime is quite a bit, how many employees could we hire for that amount? [LR283]

SENATOR LATHROP: Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Yes, Sandy, on this unit expenses, I noticed that went up considerable. Is that because you remodeled those units or kitchen expenses or would that be was... [LR283]

SANDY SOSTAD: That would be actually what they budgeted for the particular units. So what they budget for all the staff and expenses of a particular unit, that's what that reflects. [LR283]

SENATOR WALLMAN: Oh. Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: I've got a question on the educational services. Is that for patient educational services? [LR283]

SANDY SOSTAD: I have a question on that one too. I notice that that one actually did go from 6.5 percent of the total to about 12 percent of the total, and I don't know. If the agency can answer that question, I'm not sure on that. [LR283]

SENATOR GAY: Because I was assuming it would be for programming for clients, not... [LR283]

WILLARD BOUWENS: I believe, if I understand where Sandy got this number, it is for the true education costs of those clients that are under the age of 18 that we do get...we fund it from the school districts where they have been, where their legal residency is. It's an expense for us because we do have school teachers on staff and then we get reimbursed from the school district. I believe that's the item that is that cost, the educational services. [LR283]

SANDY SOSTAD: Okay. [LR283]

WILLARD BOUWENS: Because any of our training for our staff go in a different...we don't...I don't think it's classified as educational. [LR283]

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SENATOR GAY: Yeah. That would be an employee expense probably, wouldn't it, if you're doing... [LR283]

WILLARD BOUWENS: Correct. That would be just their time and then the cost of doing the training, yes. [LR283]

SENATOR GAY: Okay. And then you had mentioned, you said a 30 percent turnover rate and you said that's been going on for some time. [LR283]

WILLARD BOUWENS: Historically, that's been going on. [LR283]

SENATOR GAY: Like how long has that been? [LR283]

WILLARD BOUWENS: I've been working with this facility or this department for about 20 years and I remember that as being always the number. [LR283]

SENATOR GAY: It's been that high for that long. [LR283]

WILLARD BOUWENS: Yes. [LR283]

SENATOR GAY: That's amazing. [LR283]

WILLARD BOUWENS: And it may have changed now. I haven't looked at it recently, but that's what it used to be. [LR283]

SENATOR GAY: All right. Thank you. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: You also work with the other 24-hour care facilities. [LR283]

WILLARD BOUWENS: I do. [LR283]

SENATOR CORNETT: What is the turnover rate in the other facilities? [LR283]

WILLARD BOUWENS: I believe it's less than that, but I don't know for sure what it is. It is less than that probably just due to the nature of the service and maybe the nature of the location, I'm not sure, but it is less than that. [LR283]

SENATOR CORNETT: Thank you. [LR283]

SENATOR LATHROP: Okay. [LR283]

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SANDY SOSTAD: Okay. Now we're on page 12 and this is one that...pages 12 through about 21, this was just provided as information to you and I'm going to let Willard talk a little bit about it. This is when they have to establish a rate, a per diem rate, to bill someone to come to Beatrice. This is how they actually establish the per diem rates. When they bill Medicaid for a service at Beatrice, this is how they establish the rates. You'll see the Bridges Program in here later on; that's how they establish a per diem rate for the Bridges Program. If they bill an insurance company, this is how they establish the per diem rate. Willard can speak to it in more detail, but this is just another way of portraying what goes on at the institution, I guess, in terms of how they actually bill out their services to other entities. [LR283]

WILLARD BOUWENS: I'll just briefly say and then I'll open up for questions. Once the Legislature establishes our appropriation and the facility determines the census level they're going to serve that year, and you'll see on this first page there that's 340 when we did this at that time, then we determine what it costs for the different services, as Sandy said, so that we can bill the appropriate third-party payers. And third-party payers at Beatrice are Medicaid, private insurance companies, we have some Medicare, and then we have private individuals that pay, with the largest payer, of course, being Medicaid. So if you were to look back through this handout that's stapled together, you will see the different types of services and the rates that we have established on it. This morning you were talking about ICF/MR and then you were talking about ITS, the short-term service. We had a hospital program, we had a hospital unit there for many years and that was closed on May 1, if I remember correctly, so those costs will not show up in next year's budget. We have a...it's called an observation service, if you're paging through this with me. It's just for clients to go and have a doctor view them for whether it be medical needs or psychological needs. We also have a clinic they do that in. The outreach services, I think Senator Lathrop talked about those this morning a little bit. Those are those short-term services where we have...in fact, actually this program I think our staff go out into the field to intervene with very high level interventions that need to take place. An evaluation unit, again, these are all medical or ancillary type services that the clients get. And then the last...next to the last one, the Bridges Program is the one that's located on the Hastings Regional Center campus and that one is run by the administration at Beatrice. So what this allows us to do is to have rates to bill third-party payers and, as all hospitals do, you set a rate at the beginning of the year for your billing structure, and that's what we do with this information. And it gives you a lot of detail about what goes into their, what Sandy was showing earlier, with how much psychology goes into a service, how much nursing goes into a service. The food costs should be the same throughout the organization, except for what Senator Wallman said. We did put some individuals kitchens now rather than a central kitchen, so that could change just a little bit. But these are the costs that go into providing the care at Beatrice. [LR283]

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SANDY SOSTAD: Okay. [LR283]

SENATOR LATHROP: Senator Harms. [LR283]

SENATOR HARMS: I'd just like to say when you look at the Program 65, that's the physical plant cost. [LR283]

SENATOR LATHROP: What page are you on, John? [LR283]

SENATOR HARMS: I'm on page 12. Is that where we're at? [LR283]

SENATOR LATHROP: Okay. [LR283]

SENATOR HARMS: Are we on...? [LR283]

SANDY SOSTAD: Uh-huh. [LR283]

SENATOR HARMS: Okay. When I look at that, that seems to me to be fairly high. That's because the facilities are older? And with your plan to maybe consolidate those will bring that down, is that a place where you're able to make up some room in your budget in the future or...? [LR283]

WILLARD BOUWENS: Yeah, Senator, that is high, I think, if you were to compare us to an efficient building and facility. The Department of Administrative Services Building Division runs all the facility maintenance at all of our 24-hour facilities. This is a payment to them. They purchase the utilities for us, the heat. They maintain the grounds. They maintain the actual building structures. So we pay that out to them and then they maintain our structures for us. But all of the buildings, and I don't want to try to tell you what the process is on raising a building or surplusing it or getting of it, but just because we shut the door or turn off the lights... [LR283]

SENATOR HARMS: Oh, I understand. [LR283]

WILLARD BOUWENS: ...there's still some other things that go on with that building, so...but this is that cost for all those things. [LR283]

SENATOR HARMS: I just thought when we took the tour which, you know, it's well kept, I was presently surprised that everything looks really nice and it was clean and...but what stuck in my mind was the number of clients that we have there and the size of the facilities and the plant, it seemed like to me to be completely unbalanced and would be something that I would really encourage you to look at and maybe for us to see how we might be able to consolidate that to cut those costs. I realize that when you can move people out you still have to keep the heat on, that sort of stuff, but that cost will continue

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to go up. [LR283]

SANDY SOSTAD: And that's something, like I said earlier, that typically the Legislature has funded that. Whatever DAS says you need to pay, the institutions need to pay for the utilities and for that, the Legislature has funded that and placed it in the institutional budget over as many years as I can remember, so... [LR283]

SENATOR HARMS: I would like to go...and then I'll leave you alone, okay? Program 72 of psychology, with the...I guess with the shortage that we have and at least from what the federal report has shown us, that we're inadequate or not efficiently...have enough people to do that, I would have anticipated that if we were funded appropriately that that should go up much...be much higher in the future because that's expensive. But it is very clear that we don't have the right kind of assistance there to provide that appropriate service. Is that correct? [LR283]

WILLARD BOUWENS: Yeah, I'm not sure about what the appropriate level is, but your observation is correct, Senator. This says that it costs \$8.71 a day and so however many psychologists we have over the population that we have at Beatrice is how that's calculated out. [LR283]

SENATOR HARMS: Yeah, I understand. [LR283]

WILLARD BOUWENS: And I would agree with you that I don't... [LR283]

SENATOR HARMS: It says it's really short... [LR283]

WILLARD BOUWENS: It's pretty low. [LR283]

SENATOR HARMS: When you look at the fiscal side, it shows you where our shortfall...where we really are falling short. I know it's a difficult issue to get people to maybe go there, but that, to me, tells a story right there about adequate services, appropriate services and what we're going to have to deal with in the future. Because that's going to have to go up if we're going to meet what John was explaining to us before of his plan to address those issues. That's going to have to go up considerably. And so then, when you look at it overall fiscally, then if what you were saying, you know, Sandy, is...if we try to fund everything, the question will be where will all the dollars come from. Well, when we start looking at the plant and some of these other things, I think in the planning process those are things we're going to have to start to look at to get the right services to the people and make sure that we're on target. I mean this is really very revealing, when you see where your money is being spent, about what the issues are. So thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

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SENATOR GAY: I've got a question. When you look at all these programs and there's probably other facilities around the country, how does this compare to a like facility in another state? Have you ever looked at that, to say, boy, we're not as efficient... [LR283]

SANDY SOSTAD: I've never looked at that. [LR283]

SENATOR GAY: ...or superefficient? [LR283]

SANDY SOSTAD: I have never looked at that. [LR283]

SENATOR GAY: We've never looked at that. [LR283]

SANDY SOSTAD: We could look at it, you know, looking at regional centers or, you know, at other ICF/MRs. That's something we could look at for you, yeah. [LR283]

SENATOR GAY: The only reason I say that, you know, we were the gold standard, now we're not. But, you know, maybe it's time to look around and see what other people are doing. [LR283]

SENATOR HARMS: Senator, that's what I was talking about, the benchmarking. I mean, we're going to have to do that so that you as senators, even on the floor, when you want to debate the budget, you got to have some idea how you are with efficiency, and that's what I was referring to. And you're right on target; that's exactly what we're going to have to do. [LR283]

SENATOR LATHROP: Senator Adams. [LR283]

SENATOR ADAMS: How do we line up then in terms of Medicare and Medicaid and private insurance when we submit these base rates? Do we hear back from them that we're out of line or... [LR283]

WILLARD BOUWENS: No, we usually don't, Senator. The private insurance companies will pay, you know, they reimburse you the rate that you bill them normally with...depending on the individual's plan. And just for the record, they don't have...very many of our clients don't have private insurance. Medicare, the federal government sets those fee schedules for us. When we had a hospital, it was a prospective hospital that we updated DRGs on those. Medicaid program in Nebraska for a public-run facility like ours is a cost-based program. So while we bill a rate here of x dollars, at the end of the year, whatever is allowed by the Medicaid program, then the rest of that federal dollars is passed through to Beatrice, so...and then with private pay people, that is the rate and if they have the ability to pay full cost, they have to pay that rate or some portion of it

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based on the statutes. [LR283]

SENATOR LATHROP: Okay. I think you can continue. [LR283]

SANDY SOSTAD: Okay. Then we'll go to page 22. This is just a little brief look at the cash funds again, where they come from: clients; insurance; counties; school districts; federal funds--mainly Medicaid, a little bit of Medicare; interest; grants. And then the total funds you can see over time. It varies. Sometimes we have some federal Medicaid settlements which will make the federal funds look funny in a particular year, but you know we've been counting on overall at least, you know, \$1 million or \$2 million or \$3 million a year in terms of an increase in these funding sources to help us fund Beatrice. And we may not be seeing that kind of thing in the future then. As you move, you're going to step down a little bit in terms of your revenues for clients. [LR283]

SENATOR HARMS: Mr. Chair, could I ask a question? [LR283]

SENATOR LATHROP: Certainly. Senator Harms. [LR283]

SENATOR HARMS: I don't mean to be a pain. [LR283]

SENATOR LATHROP: No, no, I think that's a good way to approach it. [LR283]

SENATOR HARMS: Sandy, have we done any projections at all, as we start to look at going to the community-based programs and trying to see what those numbers will be, if we're successful in reaching what we said we would like to get the level down to, have we projected at all in regard to the federal loss? Because I think that's a question we're going to have to look at. This committee should be interested in knowing exactly what those costs will be because of what the recommendations you might end up making might very well be tied to some of this. And in order for us to meet what John's goals are, which I would have to say I'm hopeful we could meet those, do we have any idea? [LR283]

SANDY SOSTAD: We haven't done it. I know the agency will be doing that when they submit their budget request. I'm fairly certain they will have projected what they think is going to happen at a client level of 200 people,... [LR283]

SENATOR HARMS: Okay. [LR283]

SANDY SOSTAD: ...what we're going to lose in revenue, what kind of balances we're going to have and that kind of thing. And then the Legislature will react to that. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

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SENATOR GAY: So if we had a...let's say a patient has moved out and on the first page it's \$140,000. Where is it? Let me get to a page here. Per patient cost you had average cost per client is \$140,000 here. It's making up 12 percent of your budget. If we move...if we get their population down, though, we're also going to pick up...you're saying we're not getting revenue in. Would it be much more cost-effective in another program? Are we not going to pick up any savings? If a client is moved and can be more self-sufficient, which is the idea, what I'm hearing earlier, is that...that's less expensive, isn't it, or is it not? [LR283]

SANDY SOSTAD: The clients will move to probably a community-based program or a nursing home and then the revenue will follow the client there. So you're going to get less, quote, federal revenue at the community-based level than you would get at the institutional level. That's why we have, quote, waivers, because you waive that cost of the...the higher cost at the institution and it goes down to the community-based, the lower cost level, that Medicaid reimburses then, so... [LR283]

SENATOR GAY: Overall, though, I mean you're looking at one at BSDC (inaudible) overall budget. Wouldn't you still get some savings somewhere there? Because the federal government is going to pay less, yeah, we're going to pay less, but it's the best thing in the long run for everybody, federal/state taxpayer, plus quality of life issues, is what we're trying to get here. So in a way, I know we got to look at the numbers, but when you move people out, do we know that number? Is that number in there of the cost of the... [LR283]

SANDY SOSTAD: We'll get to that later on... [LR283]

SENATOR GAY: Okay. I'll wait. [LR283]

SANDY SOSTAD: ...in terms of when you move from Beatrice, say, \$150,000 down to a community-based program. You're going to get a lower, quote, average cost, depending upon what kind of service that they move to. [LR283]

SENATOR GAY: Yeah, that are being provided because it's... [LR283]

SANDY SOSTAD: And we'll talk about that in a little bit, so... [LR283]

SENATOR GAY: Okay. I'll wait. Thanks. [LR283]

SENATOR LATHROP: Senator Harms. [LR283]

SENATOR HARMS: I'm sorry. [LR283]

SENATOR LATHROP: No, don't apologize. [LR283]

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SENATOR HARMS: Sandy, it doesn't...when we move clients to a nursing home, doesn't mean that those costs are going to go down. They're transferred, but the costs may very well go up because of the expense there compared to where we are today. Is that correct? [LR283]

SANDY SOSTAD: That's where maybe Vivianne can address that or Willard. [LR283]

VIVIANNE CHAUMONT: I'm Vivianne Chaumont. Probably not. The cost of a nursing home is usually much cheaper than the cost of an ICF/MR. [LR283]

SENATOR HARMS: Really? [LR283]

VIVIANNE CHAUMONT: Yes. [LR283]

SENATOR HARMS: Thank you. [LR283]

SANDY SOSTAD: Okay. And then the last two pages here in just this section would be, again, we talked about John's shop, developmental disability administration. There is the 15 folks that work in that section right now and the funding for that. There is a Medicaid match for that, for the administrative component in the department. And then on page 24 you'll see the budget for the service coordinators that are out in the five areas of the state and there's approximately 222 people that do the service coordination component; again, a Medicaid match for that also. Okay? [LR283]

SENATOR LATHROP: Can I ask a question? And I may be getting ahead of ourselves a little bit, but when we talk about a Medicaid match for that service, is that part of the \$28 million that's in jeopardy with our decertification, or is this coming to us without respect to that? [LR283]

SANDY SOSTAD: I don't think that's in jeopardy. [LR283]

WILLARD BOUWENS: This is a different program, Senator. [LR283]

SENATOR LATHROP: Different program? Okay. [LR283]

WILLARD BOUWENS: Yes. [LR283]

SANDY SOSTAD: Okay. Now if we go to the next section, this is what I would call the aid to developmental disability programs. Just to give you a little brief history, back in 1967...well, back...really back in the early fifties, middle fifties, early sixties, that's when community-based programs sort of developed and they were really developed at the local level. The state really didn't get into that until about 1967 when we created a

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Division of Mental Retardation. That was in the Department of Health. And then in 1968, we had an Office of Mental Retardation. That was in the Department of Public Institutions. And then in 1973 they actually formally created regions, community-based programs in statutes. For a long, long time there were six regions, six providers and a couple private providers. Now we have, and you'll see that on one of the other pages we have, I think John said somewhere around 30-plus providers, plus we have a lot of people, individuals, that provide respite services. So you have a lot of entities providing developmental disability services in the different areas of the state. What I wanted to talk about here on the first chart, when we first funded, the state went in and began funding developmental disability programs, we put in about \$650,000 of General Funds. That was back in fiscal year '71. If you look at the chart on page 26, you can see now, and the chart on page 27, we're roughly at \$71 million worth of General Funds for next fiscal year. So the effort has increased. But what has changed is when we initially did it, General Funds were about 60 percent and local funds were about 40 percent. And now, due to the Medicaid waivers that began in about 1987, now we're seeing a reverse, where the federal funding is roughly 60 percent and state funding is roughly 40 percent. So that's what we're beginning to see. I have sort of a busy chart there on page 27. What I wanted to talk about is really focused on the last 15 years in DD services. What you'll see on the chart is probably what I would call the initiatives, in terms of what the Legislature and the Governor have funded, in terms of what we wanted to do in terms of DD services. And down towards the bottom in the left-hand corner you'll see the bills that I think were somewhat important to making these things be accomplished. I know it's little print, but it's what we like to use, and I like to use for my spreadsheet. Probably the first bill that I think was really important--they talked about it yesterday--LB830 in 1991. That bill established the DD Services Act, and in my mind it established two entitlements: first entitlement was service coordination for everyone. Every person that's eligible for DD services gets service coordination. The Legislature established that. Second entitlement was transition. Kids that graduate and are 21 receive transition. Those are the two entitlements. If you go back to the middle of this sheet on the left-hand side--skip the base; that's just stuff that I use--and you go down to the rate equity increase, transition increase, and waiting list, those are the categories that the Legislature has chosen to fund over time, in terms of developmental disability aid. So for instance, in 1995-96 Governor Nelson had a...called a blueprint back then, and he said, we're going to take the federal funds that are coming to the state of Nebraska, and we are going to fund everyone on the waiting list. And we're going to leverage...we're going to get client funds, so clients have to pay for services, also. So that was the initiative in '95-96, and that was when we began...we wanted to serve everyone on the waiting list with the funding that was provided that year. We began the intensive treatment service down at Beatrice, and transition was funded and service coordination. So that's when you began to see LB830 implemented in '95-96, through a Governor's initiative. During the same year the Appropriations Committee and the Legislature said, we have another priority; we want to do rate equity; we want all the providers to be paid, at some point in time, the same rate for the services that they provide. So the Legislature began this

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initiative, and if you look under rate equity increases, they put in \$5.6 million in '95-96 and we began moving towards using a methodology that would pay everyone the same rate for the service that they provided. And you can see over time the money that was put in for rate equity, and I know you remember the Legislature debated that again in the past year, where we put in another \$3 million in the current...in the last legislative session for rate equity, to bring those rates for every provider to the same amount. And also the increase each year is based upon the developmental tech position at Beatrice and how much that position increases each year. That's what drives the rate increase every year. If you'll notice, if you get to the far right column on rate equity, we're only at 95.5 percent for next fiscal year. In other words, we would have needed \$3 million to \$3.5 million more to be able to "fund" the rate equity mechanism to provide the rates that the methodology says that we should provide. Methodology, again, is not legislative; it is intent language only. It is nothing in statute. So if you flip to the next page, I tried to sort of summarize...yeah. [LR283]

SENATOR LATHROP: Hang on just a second, if you would. Senator Harms has a question. [LR283]

SENATOR HARMS: Rate equity. As you know, that was--bringing this up now--that was a real debate in Appropriations Committee, and our understanding was when we did that, that everybody would have at least, you know, an equal increase, and that did not happen. And there was a lot of hard feelings over that. Can you maybe explain to us, you know, what really does take place, because to be honest with you, it didn't occur. That's the thing we thought was occurring. So maybe other senators would have the same questions. [LR283]

SANDY SOSTAD: I think what...if you'll notice that we got to 100 percent of rate equity in fiscal year '04-05, real close in '06-07, a little bit less in the current year. Once we reached 100 percent of methodology for rate equity, then it became, what happens to that salary at Beatrice? So we have a position down there--it used to be DD Tech I. Now it's DD Tech II, because there aren't any DD Tech Is. So whatever happens to that salary at Beatrice, that's the percentage increase that the Legislature has indicated, if they follow the rate equity methodology, they would put in. So in the last biennium, this most current biennium, when the state bargained for that position down at Beatrice, there was a huge increase, percentagewise, and what happened to that salary. So I think over the biennium, it was roughly a 12.7 percent increase in that salary. So it would have taken a lot of money to get to that 12.7 percent increase and to make the methodology "equal" 100 percent. So the Legislature put \$3 million in last year. It probably would have taken about \$6.5 million to get to that point in time, to make this be at 100 percent of methodology. So I don't know if that answers your question. [LR283]

SENATOR HARMS: That's fine, that's fine. [LR283]

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SANDY SOSTAD: Okay. [LR283]

SENATOR LATHROP: Can I ask a question, just to make sure I understand that. There is some relationship between what we're paying in Beatrice and what we pay the providers in the community for their care. We'll talk about the formula a little later on. But what you're talking about with the rate equity increase is that if we increase salaries at Beatrice for the Tech II by 6 percent, then to follow the rate equity increase we'd have to have a like increase for community-based providers. [LR283]

SANDY SOSTAD: That's the way the methodology is working at the present time. [LR283]

SENATOR LATHROP: And last year we just didn't put enough money in to make up for that. [LR283]

SANDY SOSTAD: Right, right. [LR283]

SENATOR LATHROP: Okay. Then I think I do understand. [LR283]

SANDY SOSTAD: And what that allows is the same rate to be paid to every provider for each type of service that they provide, so. If you go to the next page, page 28, this sort of shows you over time, the last 15 years, where has the Legislature...where has the funding been concentrated. And as you can see, the priority has been rate equity. The Legislature has said, we're going to spend 56 percent of the \$126 million, \$125 million that we've put in...we spent it on rate equity; 23 percent, because that was an entitlement--that is in state law--went to transition, for those kids coming out of high school. And when we had some money, 24 percent went to address the waiting list. So you had those competing needs in the area of developmental disability funding. Where are you going to put your money? And I think the Legislature has--at least the Appropriations Committee--has looked at, we wanted to keep the provider rates at a certain level. We want to make sure that we have the providers out in the community, so they have emphasized the rate equity, at least from my perspective. That has been where their emphasis has been over the last 15 years, other than the entitlement that we feel like we have to fund, so. Okay, the next chart would show you--this was done, I believe, by Don--but it would show you the change in the transition funding for high school graduates as we began funding it in '95-96. You can see the number of graduates that came in and have been funded by roughly \$27 million to \$29 million probably now in this current year, in terms of transition funding. Again, that is a statutory requirement, or we look at it like a statutory requirement. It's an entitlement for those kids. We talked a little bit this morning about what I would call the gap in services. I would say the school districts tend to keep the kids in school until they reach 21, so that they don't have that gap in services, because they have to be 21 to access the services in the system. We've had bill in past legislative sessions, not real recent, where we

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actually had said, okay, we're going to fund them if they graduate at age 18. But we're talking, then, probably a fiscal impact of somewhere around \$7 million, \$8 million to fund them if they graduated at 18 and not have that cliff effect, you know. So you will see a lot of these kids stay in school till 21, to retain those services, so. The next page, page 30, this is a snapshot view of the last year that we paid--not the current year, but last year--actual payments that went to the DD providers. That shows you a list of the providers. You'll see that, like Region V, is the initial one, Region VI is the second provider, Region IV is the third provider, and then we get down to Region III--it's right in there--and then you see Regions I and II. So the regions are still the primary recipient, I guess, of funds. And then you have some private providers that also provide a great deal of services. So that shows you how the funds go out in terms of aid, who the providers are. [LR283]

SENATOR HARMS: Mr. Chairman, I... [LR283]

SENATOR LATHROP: Yes, sir. I'm sorry. [LR283]

SENATOR HARMS: Sandy, on these the (inaudible) contracts, what we have here, how do we actually supervise those? And secondly, how do we follow up to determine whether or not the contract requirements are absolutely being met? Because I have some...I just have some concerns about that. And so, how do we do that, and are these being met? And who supervises that and... [LR283]

SANDY SOSTAD: I think that's what Don was getting at this morning, the oversight. The oversight is through the contract mechanism. Maybe Willard or Don can speak more. [LR283]

DON SEVERANCE: Okay. Oversight as far as the billing, or... [LR283]

SENATOR HARMS: I'm just saying that when you have a third-party contract to provide services, you enter to them with a contract? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR HARMS: You know, I'm just saying, how do we know that they meet all of the contract requirements, and who goes out and monitors that, to make sure that the dollars are being spent appropriately in every place? [LR283]

DON SEVERANCE: Okay. Service coordination on an ongoing basis goes out and monitors to make sure...because part of what...the contract says that they'll provide what is in the IPP for the individual. So the service coordinator goes and makes sure that those services are actually delivered. They do formal monitorings and they do informal monitorings, both. We also have a certification process. We go out and certify

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the providers, where they go through and look and make sure that everything is done appropriately. For that, it's done at least biannually. [LR283]

SENATOR HARMS: Is there a final report that shows that, in all of Health and Human Services third-party contracts, that shows that...whether they've met the requirements, beyond just this one? [LR283]

DON SEVERANCE: The provider profile that we handed out actually tells you what their accreditation is or whether they got a one- or two-year certification, so. [LR283]

SENATOR HARMS: Well, what I'm saying is, have they met what they said they would do,... [LR283]

DON SEVERANCE: Um-hum. [LR283]

SENATOR HARMS: ...in the contract, all across the board? That's okay. Leave it at that, I'll... [LR283]

DON SEVERANCE: Okay. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Would that be...could the State Auditor, as well, follow up on that, too, because just recently...the State Auditor at any time...or how does that work? Could he come in and say, we're not getting what we're paying for here? And that happens a lot. So is he the final...he could look into this, too, right? [LR283]

DON SEVERANCE: Well, he could, yes, in the case you're talking about... [LR283]

SENATOR GAY: Just not every day, but... [LR283]

DON SEVERANCE: Yeah, we kind of identified some issues and asked for some assistance. [LR283]

SENATOR GAY: So you have that backup. [LR283]

SENATOR LATHROP: Okay. [LR283]

SANDY SOSTAD: Okay. The next couple of pages here I'll probably defer to Vivianne or the other folks. This is just basically some of what you saw yesterday. It lays out the development disability waivers that we have, the number of slots, the slots used, the percentage used, what kinds of services they get. (Cell phone ringing.) Okay. (Laughter) And this is as of May of 2008. (Cell phone ringing.) The only thing I totaled up at the

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bottom is the total slots approved and the slots used, and we're using roughly 81 percent of the slots that we have available, and maybe the agency could address, you know, why aren't we using all the slots? Or is this good, is this not good, in terms of, you know, what we have available? [LR283]

SENATOR LATHROP: If I can interject, maybe you could tell us...give me the background on what a waiver is, since I'm not over in Health and Human Services Committee. And just as a matter of background, since we're about to talk about waivers, explain how that works. That's a federal government Medicaid sort of thing; am I right? [LR283]

VIVIANNE CHAUMONT: Yes, it is. [LR283]

SENATOR LATHROP: Maybe you could share that, a little background, please. [LR283]

VIVIANNE CHAUMONT: Okay. Vivianne Chaumont, HCBS, Home and Community-Based Services waivers, are what's known in Medicaid as 1915(c) waivers. And basically, what this waiver does is it allows the state to provide services that the state might not otherwise pay for the rest of Medicaid clients, in order to effectuate cost effectiveness in delivery of services in the community, as opposed to an institution. So in other words, what the standard is, is that you have to look at a cost-effectiveness analysis to say that the person in the community would be less expensive to care for than the person in an institution. And therefore, since there's going to be savings, both to the federal government and to the state government, we're going to go ahead and pay for services which are not necessarily for general Medicaid services because they're not medical in nature. Medicaid pays for services that are medical in nature. So that's what a 1915(b) waiver. Now the state can limit enrollment, and that's what slots are. So you ask the state...you ask CMS in the waiver how many slots you're going to have, how many people you're going to have in the waiver, and you can limit it, which is usually not something that is allowed in the regular Medicaid program. You don't get to say we're only going to serve 300 people in Medicaid. So that's...those are really the two things that you offer services that are not normally covered by Medicaid, and you offer...and you can limit it and there's a cost-effectiveness analysis that's involved. [LR283]

SENATOR LATHROP: Where does the waiver come in? Who is waiving what? [LR283]

VIVIANNE CHAUMONT: What you're doing is you're waiving general Medicaid requirements that say you have to offer "statewideness," you have to offer the same services to everybody across the state. You don't have to offer these services to everybody across the state. You can limit it to a population, specific population, and you can limit the number of people on there. So you're waiving normal Medicaid requirements. [LR283]

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SENATOR LATHROP: And what we do with a waiver is we essentially say to Medicaid, this is our idea, but we need to have you waive some of the requirements that Medicaid has with respect to the delivery of services. [LR283]

VIVIANNE CHAUMONT: Exactly. [LR283]

SENATOR LATHROP: When you have a waiver--I've heard the term used...with respect to Medicaid, I've heard the term used in a program that with the waiver you get money. So are there programs that if you do a waiver or you request a waiver, it's approved, then there's money that comes from Medicaid, or am I misunderstanding it? [LR283]

VIVIANNE CHAUMONT: Right. If you get your waiver approved, then you get federal matching funds just like a Medicaid, so that these waiver services, these DD waivers, are matched by the federal government, just like inpatient hospitalization would be. [LR283]

SENATOR LATHROP: So by asking for a waiver, there must be some inducement from the federal government to ask for a waiver; am I right? [LR283]

VIVIANNE CHAUMONT: The inducement is the cost savings. [LR283]

SENATOR LATHROP: Okay. [LR283]

VIVIANNE CHAUMONT: And the fact that now you're offering services in the community which is, you know, now seen as the best way to provide services for people. [LR283]

SENATOR LATHROP: And is that savings...if we ask for a waiver, then we're given permission not to do something, do we save more than the federal government, so therefore we come out ahead? [LR283]

VIVIANNE CHAUMONT: We come out ahead, but we don't save any more than the federal government. If you have somebody in a nursing home that we're paying \$5,000 a month for, and then you move them as a result of this waiver into the community and you provide things like chore services, you allow them to have their house...you know, help them have their house cleaned, you get groceries, you help them with the laundry, have somebody come in and do their medication, that kind of thing, those are not medical services. But they're allowing that person to be at home, say, instead of in an institution, so maybe they cost \$3,000 at home. So you just saved \$2,000 on that client, and then so the federal government saves 60 percent of that \$2,000, and the state saves the 40 percent of that \$2,000. [LR283]

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SENATOR LATHROP: So the advantage to us in a waiver is we're saving part of the overall cost that we share with the federal government. [LR283]

VIVIANNE CHAUMONT: It's the cost effectiveness and the quality of life, both those two things. [LR283]

SENATOR LATHROP: You have...and I'm not looking necessarily at specific lines in here, but you have slots approved, slots used. Do we have to...when we get this waiver, do we have to say, we want to do this is X number of people that are currently receiving Medicaid benefits? [LR283]

VIVIANNE CHAUMONT: For any home and community-based services, you tell them how many slots you want, and then you can't go above those slots without asking for permission to expand. [LR283]

SENATOR LATHROP: Okay. You answered my question, or at least you gave me the background I'm interested in. Senator Stuthman. [LR283]

SENATOR STUTHMAN: Vivianne, does a client request the waiver, or does the federal government grant a waiver? [LR283]

VIVIANNE CHAUMONT: The Medicaid agency usually requests a waiver of the federal government; says, we want to run this program. Will you go ahead and approve it? And it's a lot of paperwork and a lot of approval process, and then the federal government says, okay, this works for us, as well; you can go ahead. And then clients can apply to be in...to receive the services that are in the waiver. [LR283]

SENATOR STUTHMAN: So you as the department would request a waiver from the federal government, because you can see a cost saving and a need in that community and in that service? [LR283]

VIVIANNE CHAUMONT: Correct. [LR283]

SENATOR STUTHMAN: Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Vivianne, when you get those waivers, though, how often do they say--or maybe they don't--they say, oh, by the way we're not going to do that anymore? Do you get notices that say, we granted you a waiver four years ago, but we're not doing any more? Are those kind of permanent things, or... [LR283]

VIVIANNE CHAUMONT: We haven't seen that at all in the home and community-based

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services. [LR283]

SENATOR GAY: In other...for other things, other waivers, though, that we apply for, do they ever come back and say, oh, by the way, you're not getting the ten of these. [LR283]

VIVIANNE CHAUMONT: The only other waivers that I can think of are...there's family planning waivers and there's managed care waivers, and I've never known the federal government to back off. [LR283]

SENATOR GAY: So they're fairly...they're permanent, fairly permanent. We're saving money, so they'd want to continue? [LR283]

VIVIANNE CHAUMONT: Yes. And actually they recently have made some of these waivers, then they put it in the state plan so you don't have to keep renewing it every, I think it's five years for the waivers, and it's a lot of paperwork and a lot of...so yeah. I think the federal government is very committed to these programs. I've never seen that. [LR283]

SENATOR GAY: Okay. [LR283]

SENATOR LATHROP: Good. Okay. Sorry to interrupt, but I didn't understand the whole waiver business, so. [LR283]

SANDY SOSTAD: Well, and I guess the only question I would have of Vivianne is, you know, in the first waiver here, the home and community-based, the comprehensive waiver, we're using about 90 percent of that waiver. And then in some of the ones...I know the last one, the community supports, that's a relatively new waiver we just got. But the ones in between I was just curious about the utilization. Why wouldn't we be using most of those slots, or... [LR283]

VIVIANNE CHAUMONT: That's not a question for me. The Medicaid division is the single state agency that has to put forth the waiver, but in the state of Nebraska the Division of Developmental Disabilities administers the DD waivers, and so it would be a question (inaudible). [LR283]

DON SEVERANCE: Yeah. So we have asked for slots to be increased. On some of them, like the community supports waiver, that just started, so that number is going to increase and we will be using more of those slots. The children's waiver just got increased; it was at 250, and we were always using all the slots so we wanted them increased so that we'd get more children on the waiver. So that's part of why that's not being used as high. So for the most part, yeah, we try to use all the slots that we can, because we're trying to maximize federal funding. [LR283]

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SENATOR LATHROP: Senator Gay. It's getting...long morning. [LR283]

SENATOR GAY: Thanks. If we're going back and forth, then, and DD asks for...we have the waivers set up now. We went to the (inaudible), set up the waiver. We have the list. That's why I'm saying if there were 40 people on a list for one of these...and if one of these waivers would work for them, how do we coordinate between Vivianne's office and your office, that we're filling these slots? Because it seems to me like a lot of work. You know, we have them available, let's go use them. So are we actively pursuing that, where we're going to get these filled up, do you think? [LR283]

DON SEVERANCE: Well, yeah. We're actually pursuing it. We have disability services specialists out in the field, and we're going to review every person to see whether or not they would be eligible for the waivers, for whatever the appropriate waiver is for the service they could receive. And so they'd make the effort to go and get the person signed up for the waiver, yeah. [LR283]

SENATOR GAY: Oh, they do? [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR GAY: And then they tell you, we're making headway on...let's say this home and community-based supports, community supports for adults. So we've got 200 slots approved. We've only used 59, but we're making good progress then. So they're out actively today or any other day trying to find clients to go fill these slots? [LR283]

DON SEVERANCE: Yeah. Actually, on that one, that's a new program and virtually everybody that's in that program is on that waiver. So as we get more people to take the service, then we'll get more people on the waiver at the same time. [LR283]

SENATOR GAY: Yeah. But I guess what I'm looking for is the assurance that we're out actively moving our list and trying to fill these, when we can. I mean, obviously some clients wouldn't qualify for some of these things, but the ones that do, we're...every day, these people are out...employees are out working hard to get them filled, right? [LR283]

DON SEVERANCE: Yeah, yeah, because it goes and stretches our budget. The more federal money we have, the more people we can serve, so. [LR283]

SENATOR GAY: But it's a winner for everybody, though, like we said. [LR283]

DON SEVERANCE: Yes. [LR283]

SANDY SOSTAD: And the next sheet was provided by Medicaid. I don't know if

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Vivianne wants to say anything about this, in terms of how Medicaid funds the claims paid in the fiscal year 2007. [LR283]

VIVIANNE CHAUMONT: I'm Vivianne Chaumont. This is just a sheet that tells every Medicaid expenditure that we've had for clients who are developmentally disabled. And the first five columns are the clients by waiver. So what we expend, you start at the top, what the waiver services cost, what the DD services coordination--which are the 225 people, what they cost--and then a subtotal of what the medical services are, because if you're a Medicaid client, you obviously are not just eligible for the waiver services, you're eligible for regular Medicaid services. So you're talking about prescription drugs, nursing facilities, home health--all of the different medical services that Medicaid pays for. And then the very last column is the costs that we have for people who are not...DD clients who are not on a waiver, and so those would be people in ICF/MRs, and then how much money for the medical services we spend. So altogether, Medicaid spends about \$250 million a year on DD services, including waiver services, ICF/MR payments, and medical services. [LR283]

SANDY SOSTAD: And that is general and federal funds, the \$250 million. [LR283]

VIVIANNE CHAUMONT: Forty percent of that would be state funds, and 60 percent of that would be federal funds. [LR283]

SENATOR LATHROP: Yeah. I think you did say that the federal government...so the total amount is \$250 million a year? Where in this do we see the money that was put in jeopardy by our decertification? Is that on that... [LR283]

VIVIANNE CHAUMONT: That would be the Beatrice, payments to Beatrice. So that would be... [LR283]

SENATOR LATHROP: On page 32. Is it found on page 32 in one of those numbers? [LR283]

VIVIANNE CHAUMONT: It would be some of the money that's the very...let's see, the sixth column, the nonwaiver, and that intermediate care facility, second line down, \$64 million. That is private ICF/MRs plus Beatrice, so that would be some of that. [LR283]

SENATOR LATHROP: So that's where the \$28 million is, or whatever the number is? [LR283]

WILLARD BOUWENS: Yes. [LR283]

SENATOR LATHROP: Thank you. [LR283]

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SANDY SOSTAD: Okay. And then the last...just the last two pages are...sort of really quick, but gives you an idea. Page 34, community-based providers, we talked about the rates they're paid. They're paid a different rate based upon the kind of service they provide. These rates are units based on units of service, so they would have to speak a little bit what the units of service are. But if you provide this unit of service, then you're paid this rate. These are the rates that go up by the percentage that the Legislature puts into the rate methodology. If you flip to the last page real quickly, it tells you the average cost by waiver. So if we put a person in a community-based program on the comprehensive adult waiver, which would be very close, as close as you could get to what Beatrice would have without some of the medical components, you're talking around \$50,000 in the community versus maybe \$150,000 at Beatrice. So there's your comparison there. And depending upon what services, what array of services a client needs, you would have different average costs for that client. But Don worked on these numbers and he could maybe answer some questions, if you have, on that. [LR283]

SENATOR LATHROP: I think this would be a good time to break for lunch. (Laughter) We've kind of gotten in your presentation to the community based and the cost of community-based care, and that's going to segue into the formula. And I think...are you going to talk about that too, Don? I see John raising his hand. The two of you are going to tag team--talk about the formula for determining how much money will follow a patient into the community-based care. So perhaps we can take up the last two pages of this presentation, ask questions, and go into the formula after lunch. All right? So let's return at 1:30 p.m. [LR283]

SENATOR LATHROP: We're right where we left off, except that we lost Vivianne, right? [LR283]

JOHN WYVILL: Yeah, I think we lost Vivianne. [LR283]

SENATOR LATHROP: Okay. I see you brought a flow chart. Maybe we'll get to the flow chart after we cover the last page, and that was something we were hearing from you on. Is that right? [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: Good. Why don't we...go ahead, Don. [LR283]

DON SEVERANCE: Okay. Community providers unit rates are on page 34. Those are basically the rates we pay per hour of service provided to individuals and services. So it would be kind of comparable to the number of staff hours per provider that are provided. The rate also includes additional payment for training, supervision, administrative costs, facility costs, other costs that are...go into it. So there's quite a bit that goes into a unit rate. And that's why they vary somewhat between assisted and supported day versus

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assisted/supported residential, because there are just different components that go into them. [LR283]

SENATOR LATHROP: Okay. We're going to ask you to talk into the mike and be a little louder. [LR283]

DON SEVERANCE: Okay. [LR283]

SENATOR LATHROP: They're cupping their ear like this in the back row. [LR283]

DON SEVERANCE: Okay. [LR283]

SENATOR LATHROP: You're fine. Let me ask you a question then, and not to get too far ahead of ourselves, you're going to talk about a formula for deciding when a particular person with developmental disabilities goes into a community-based program. Does that formula then give us some fraction or multiple for this unit rate? [LR283]

DON SEVERANCE: Yeah. Basically, the way we do it is the formula for the OAP, that we'll be talking about later, will actually kind of give you an overall amount, and then that's divided out by the rate, unit rate amount. So it tells how many units of service a person would receive. [LR283]

SENATOR LATHROP: Okay, okay. So just to give it some context, we'll talk about the formula shortly, but this is the unit rate, or this is the summary of the unit rates for the last several years. [LR283]

DON SEVERANCE: That's correct. Okay. And the back of the sheet just has...we talked about waivers this morning. And also people that are on state aid or just DD aid, state funds. And so this gives kind of the average cost for people on each of the waivers. Children's waiver is just basically a residential waiver, because they're receiving day services through school, service coordination, just service coordination. The DD aid could be any combination of services. The comprehensive adult waiver would be both day and res., which is why it's closer to \$50,000. The adult day waiver, again, would just be for day services, and the adult residential waiver would only have residential services. That amount under the total really is kind of inaccurate. I think the average for everybody in services, as far as off these waivers, is around \$34,000. [LR283]

SENATOR LATHROP: Okay. Okay. Thank you for that explanation of the last two pages. Let's see if it provoked any questions? Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. When you just stated the average cost per client or whatever, or the one receiving services is \$34,000 a year? [LR283]

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DON SEVERANCE: Yeah, for people in community-based...yeah, what I'd call hard services. [LR283]

SENATOR STUTHMAN: In community-based setting, services provided cost whoever pays \$34,000? [LR283]

DON SEVERANCE: On average, yes. [LR283]

SENATOR STUTHMAN: On average. Okay, thank you. [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: When you look at these, though, let's say a comprehensive adult waiver, which is you said residential services, day services, just what it says, comprehensive, where is it that...is there anything that you might have handed out and I just don't have it in front of me that says what each one of these things is and how you qualify to get in there? You know, if I had a person that wanted to get in there, all the different things I have to meet to be able to not only get on the list, but then get through the list and start receiving services. Do we have that somewhere? Did you hand that out to us? [LR283]

DON SEVERANCE: No, we didn't hand that out but could probably come up with something for you. [LR283]

SENATOR GAY: At some point, I think that would be good for everybody. Because, I mean, I know you guys...your staff, you deal with these things all the time. But here we are trying to figure this out. And it would be nice to say exactly what a children's waiver encompasses. So it doesn't have to be today, but that's something that I think would be very helpful as we look through all this data, so we know what we're paying for, you know. [LR283]

SENATOR LATHROP: The criteria. [LR283]

SENATOR GAY: Yeah, the criteria of getting on there, yeah, and what's provided out in the community. Because I know some of the things, you know, I'm no expert at all by any means, but I kind of know some of the things that are happening in the community. But it would be kind of good to have a better summary. You handed out a book of all the services that are being provided by people, what that means though doesn't do me much good, unless I know what these things mean. So... [LR283]

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DON SEVERANCE: Okay. We'll get that to you. [LR283]

SENATOR LATHROP: Any other questions? Sandy is still in the crowd, I see, and I wondering if anybody needs to have her come back to answer any questions before we move on to the organizational chart? Doesn't look like it. All right. Thank you very much for your presentation. It was very, very helpful. We have John Wyvill back to talk about the organizational chart and, I guess, to answer questions for us. [LR283]

JOHN WYVILL: (Exhibits 3 and 4) Yeah, the organizational chart and OAP. I'm John Wyvill, director of Developmental Disabilities, for the record. Need...before we touch on the organizational chart, need to give you some hard numbers that we have at the request of Senator Lathrop about people since March, where they're going, placement outside of BSDC. We have 22 that are going into a nursing facility, and we have 13 for DD community providers, and we have two deaths at that time. Also, at one time Senator Gay had requested a tally of how we track where they're going. This is just a simple redacted chart. We will give each one of you members something in the mail in the next couple of days that shows you where the placements are going without the client identifier. And that will be there. And if you want to have any questions about that, that will be helpful for you for the record. [LR283]

SENATOR LATHROP: And if you could provide Beth Otto with a copy of that, so that we can get it into the record, that would be great. [LR283]

JOHN WYVILL: Will do so. Yeah, okay. [LR283]

SENATOR LATHROP: That document that you were just talking about, that explains where each of the 22 people, what nursing homes they went into? [LR283]

JOHN WYVILL: Nursing homes, developmental disability facilities, things like that. And we'll track it all the way back since December. [LR283]

SENATOR LATHROP: Okay. [LR283]

SENATOR GAY: Are you going to send those to the offices, not our home? [LR283]

JOHN WYVILL: Yeah. [LR283]

SENATOR GAY: Yeah. Okay. [LR283]

JOHN WYVILL: Yeah, yeah, won't send them home. [LR283]

SENATOR GAY: Okay. [LR283]

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SENATOR LATHROP: Our dining room tables are covered with stuff. [LR283]

JOHN WYVILL: Understand. I'm the same way. [LR283]

SENATOR LATHROP: As long as we're on that subject, and before we go to this, let me ask you about the folks that went into nursing homes. When we take somebody from a Beatrice-style setting, where they're getting habilitation, and go to a nursing home, there is no pretence that there is habilitation going on in the nursing home. Would that be true? [LR283]

JOHN WYVILL: That's correct. There's nursing level of care; however, money follows the person. We will be, if we have not already, follow up to see if any of them will be interested in community placement after the next step. So if not, nursing home, and that's it. It just depends on the individual. But that's the guardian's preference. [LR283]

SENATOR LATHROP: But when we send...when we place somebody in a nursing home do we necessarily have to first conclude that they're not capable of habilitation? [LR283]

JOHN WYVILL: They have PASSAR. They do the PASSAR with... [LR283]

SENATOR LATHROP: I'm sorry, I didn't understand. [LR283]

JOHN WYVILL: PASSAR, P-A-S-S-A-R, which is another assessment to see their abilities. And they have to pass PASSAR to get into a nursing home. [LR283]

SENATOR LATHROP: And does that mean they've developed all the skills that they can, or they've hit some plateau, or does it mean they're not capable of learning any skills? What's passing the PASSAR mean? [LR283]

JOHN WYVILL: That they are eligible for nursing home level of care. [LR283]

SENATOR LATHROP: And what does it tell us about their skills or their ability to learn or their needs? [LR283]

JOHN WYVILL: I believe it...I don't know the exact answer. But I believe it's not able to improve any more. [LR283]

SENATOR LATHROP: Okay. And in each of the 22 placements into a nursing home, a guardian has agreed to that? [LR283]

JOHN WYVILL: That's correct. [LR283]

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SENATOR LATHROP: None of those were involuntary? [LR283]

JOHN WYVILL: Yeah. Yeah, that's correct. Now there's some that wanted nursing home placement and did not pass the PASSAR, so they have to either consider staying at BSDC or looking at community-based (inaudible). So it's a safety net so we're not pushing people into nursing homes. [LR283]

SENATOR LATHROP: Good, good. Thank you. And, I guess, you can explain the organizational charts for us. [LR283]

JOHN WYVILL: Yeah. Senator Harms had requested an organizational chart. An organizational chart, which is a draft, which was 5-28-08. Organizationally we have made some changes. Just so you know, Senator, we consulted with my...I belong to a development disabilities directors organization, and they put me in contact with nationally recognized experts, such as Liberty Healthcare. And after consulting with them and others, we have reconstituted the management team and how we're doing it to be consistent with best practices in ICF/MRs. And this is what we have, is we have the chief executive officer, and then we have a project manager, and then we have several senior managers underneath. The medical director, which is an interim right now, we are going to be, hopefully, making an announcement within the next week or two of an appointment of a new medical director. The quality improvement manager, active treatment administrator, and neighborhood services administrator, we're doing a nationwide search to fill and place those, probably from someone outside the state of Nebraska will be coming in to do those services. And then we have the facility operations, and then you see the breakdown in terms of how the areas are organized. And that's the organizational chart you requested. And just as an added bonus, we just threw in the Division of Developmental Disabilities one to show you the long-term care service coordinators that work throughout the state. [LR283]

SENATOR HARMS: Thank you very much. [LR283]

JOHN WYVILL: Okay. [LR283]

SENATOR LATHROP: Give them just a second to read it. [LR283]

JOHN WYVILL: Okay. [LR283]

SENATOR LATHROP: See if that provokes...bring up any questions. Maybe while they're doing it, can you...we haven't talked...we've talked a lot about Beatrice, but not a lot about Bridges. And Bridges is actually part of Beatrice State Development Center, but it's found at the Hastings Regional Center. Am I right? [LR283]

JOHN WYVILL: Um-hum, that's correct, Senator. [LR283]

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SENATOR LATHROP: Can you just tell us what's special about the Bridges Program or identify the clients and the reason people go to Bridges? How many beds you have? [LR283]

JOHN WYVILL: The reason that they go to Bridges is they're the most violent offenders that pose a risk to themselves and others and/or sexual predators or perpetrators. And that is the safest place for them and for the community to be at. [LR283]

SENATOR LATHROP: They are folks with developmental disabilities who are...have... [LR283]

JOHN WYVILL: That's correct. [LR283]

SENATOR LATHROP: ...have... [LR283]

JOHN WYVILL: Have...if they were not there, they'd probably be in jail or, unfortunately, even worse circumstances. [LR283]

SENATOR LATHROP: And what are...what's the capacity of the Bridges Program? [LR283]

JOHN WYVILL: I believe it is 12. We have 14 beds, but it's usually operating under 12 or 13 people that are clients. [LR283]

SENATOR LATHROP: So we have more capacity than people? [LR283]

JOHN WYVILL: One more. I think I said that wrong. We have 14 beds; I think we have 12 or 13 clients. [LR283]

SENATOR LATHROP: Okay. And I don't want to open this completely up, this can of worms, but the Hastings Regional Center, what's there besides the Bridges Program? [LR283]

JOHN WYVILL: Senator, I couldn't tell you. I'm just focused on the Bridges unit. I know they have behavioral health there. [LR283]

SENATOR LATHROP: As we begin to have vacant cottages at Beatrice, does it make sense to move the Bridges Program there, or do we have to have fence around these people? Or why is the Bridges in Hastings and not on the campus of Beatrice State Development Center? [LR283]

JOHN WYVILL: I think that was a decision they made prior to me coming here. I think

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the unit was created, if memory serves me correctly, in response to a developmental disability client stabbing, a community-based client stabbing, I think, a five-year-old child. And there was a movement out there to identify those risks and put them in a more secure setting so that they wouldn't do it. And I think that predates me for some considerable time. And there really hadn't been much discussion about that. Senator Flood has expressed some interest in moving that facility up to Norfolk, but... [LR283]

SENATOR LATHROP: Right, and that's my concern is that we have the Bridges there. And I don't know if...we hear, from time to time, just talk on the floor, if I can use that, that Hastings doesn't have anything going on but the Bridges Program. We got a whole lot of staff and we have just a few people receiving care. But you're not the guy to answer those questions. [LR283]

JOHN WYVILL: Well, it's...they're high-risk clients. And they... [LR283]

SENATOR LATHROP: And that I can appreciate. But having a whole facility for 12 or 14 people, while we have empty buildings at Beatrice, I was just... [LR283]

JOHN WYVILL: Yeah. I would not be...to be candid, Senator, I would not feel comfortable with them being on BSDC campus right now. [LR283]

SENATOR LATHROP: Okay. Senator Cornett. [LR283]

SENATOR CORNETT: You may not know the answer to this. Bridges is for the developmentally disabled, correct? [LR283]

JOHN WYVILL: The Bridges Program, yes. [LR283]

SENATOR CORNETT: Bridges Program, yes, for the developmentally disabled that are dangerous. [LR283]

JOHN WYVILL: Yeah, dangerous or...yeah. [LR283]

SENATOR CORNETT: Danger to themselves or danger to the community. [LR283]

JOHN WYVILL: Yes. [LR283]

SENATOR CORNETT: Where are people that are mentally ill but not developmentally disabled that are dangerous, whether to themselves or to others, placed? [LR283]

JOHN WYVILL: I would think Lincoln Regional Center or others. [LR283]

SENATOR LATHROP: Regional Center. [LR283]

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SENATOR CORNETT: Is it the regional? [LR283]

SENATOR GAY: And Norfolk. [LR283]

SENATOR LATHROP: Norfolk would have this...the sexual... [LR283]

SENATOR CORNETT: Predator. [LR283]

SENATOR LATHROP: ...predator types and Lincoln Regional Center. [LR283]

SENATOR CORNETT: That's it. [LR283]

SENATOR LATHROP: Okay. Any other questions, organizational chart or the Bridges? Okay. Then I think our next assignment is to learn something about this formula. [LR283]

JOHN WYVILL: Okay. [LR283]

SENATOR LATHROP: I'll encourage you one more time to put the mike closer while you're talking, so the volume is being broadcast in the room. [LR283]

JOHN WYVILL: Okay. Sorry about that, Senator. The next thing that I wish to address is the question about how funds are allocated to persons in community services. In 1991, the Legislature passed into law the Developmental Disabilities Service Act, LB830, which specified that the state develop a policy which ensured the adequate and equitable distribution of financial resources based on a consistent rationale for reimbursement that allows funding to follow service recipients as their service needs change. This is also referenced to in statute as the objective assessment process. Work on this process began in 1996, and formulas for determining the funding for individuals was developed shortly after that time based on information regarding people's utilization of services as predicted by assessment of their ability. The basic idea behind the objective assessment process, or OAP, is that persons with greater abilities will need less support, and vice versa. The guiding principle of the OAP are to provide equitable funding through a revenue-neutral redistribution of available resources that is based on the abilities of the individuals versus the need of the provider. It is designed to allow the person to take the funding from one provider to another should they do so. It is also designed to allow for changes in a person's ability or circumstances, as well as aiding the division in management of its resources. This methodology was modeled off of and developed in consultation with other states who have addressed this issue. Thus, the OAP is comparable to what many other states are doing to ensure an adequate and equitable distribution of resources. I'm not going to go into the detailed explanation of the formula developed as part of the OAP process due to the complexity of the

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statistical procedures used in the development. There are separate formulas for day and residential services as the mix of abilities that affects the supports a person needs varies somewhat between the two services. What a person needs for support in gaining meaningful employment is somewhat different from support the person needs to live with increasing independence. [LR283]

SENATOR LATHROP: John, can I interrupt you just for a second? Are you working off a handout? I see everybody up here looking around through their stuff. Just so that we can follow along. [LR283]

JOHN WYVILL: You should have in your booklet my testimony. I'm sorry. [LR283]

SENATOR LATHROP: That's all right. That's in this book? [LR283]

JOHN WYVILL: Yes. [LR283]

SENATOR LATHROP: And what's it under or what's the tab? [LR283]

SENATOR ADAMS: It's under that first tab. [LR283]

JOHN WYVILL: I'm sorry about that, Senator. [LR283]

SENATOR LATHROP: No, that's all right, that's all right. I just saw everybody up here digging through their papers. [LR283]

BETH OTTO: It's not the very first page. You go down a few pages and then it's (inaudible). [LR283]

SENATOR LATHROP: Okay. What's on the front? [LR283]

SENATOR GAY: Objective Assessment Process. [LR283]

SENATOR LATHROP: You can continue. I'm sorry to interrupt you, John. [LR283]

JOHN WYVILL: Oh, that's okay, that's okay. [LR283]

SENATOR CORNETT: We were just trying to keep up with you. [LR283]

BETH OTTO: Do you have extra copies? [LR283]

JOHN WYVILL: I just have one more paragraph, so if that helps. [LR283]

SENATOR LATHROP: Oh (laugh), all right, go ahead. [LR283]

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JOHN WYVILL: There are...and I think, with all seriousness, I think the meat and potatoes of this is more the questions and answers process, which is why I have Don Severance here to help assist with that. The OAP was implemented in 1999 for service...for persons new to services, as well as those who request increased support within their current services. This is not to say that everyone is happy with the process. As the redistribution of available resources means some people will have to give up some of their support in order for others to have increase to ensure equity, there are those who have been resistive to fully implementing the process. We have made efforts to work with all interested parties to improve the process, and will continue to make efforts to improve the process while retaining the guiding principles and goals specified in statute. And as a handout that you have is the objective assessment process that has the description of the development of the formula used in determining the level of support. And I open it up for any questions or comments or further information that will be helpful to you in understanding the OAP process. Yes, Senator. [LR283]

SENATOR LATHROP: Oh, I'm sorry. Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. I went over this the other evening when I received this stuff. And in order to, you know, get the day services level of support in dollars, the pluses and the minuses and the factors and everything like that, does it come down to what one person thinks of the individual as how they assess the individual as far as how many support dollars? I mean, the independence index, motor skills index squared, general maladaptive index, and unusual or repetitive habits severity, how do you come up with this stuff? (Laughter) [LR283]

DON SEVERANCE: I think a lot of people have asked that question over the years. The primary instrument we use to assess people's ability is called the Inventory for Client and Agency Planning, or the ICAP. And so all these different things that you're going off of are different scales, scores, and things like that off the instrument. How we do the assessment is service coordination does the assessment. They have to interview at least two people, you know, and at times they interview three or four different people independently, so that they get independent ideas of what the person is like, plus reviewing all the records that we have on the person, so they can verify the information. So we're trying not to have it just be based on kind of a whim, you know. And I understand your question. [LR283]

SENATOR STUTHMAN: But it's one or two individuals assessing someone else and making a determination and trying to weight in all of these factors, right? [LR283]

DON SEVERANCE: Yeah, based on all the information they can gather about the person. Yes. [LR283]

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SENATOR STUTHMAN: I think after you get all this plus and minuses together, you'd be ready for the mental institution. (Laughter) [LR283]

DON SEVERANCE: Computers help a lot. You know, realistically...I mean, this goes in, you know, the scores go into a program for the ICAP. And then those we use along with another computer program to go ahead and compute all that. So it does happen that way. You know, realistically we've made efforts over the years to try and improve this as far as the quality of the assessment. A lot of assessments that are done by psychologists and other people are just done with a single interview with somebody, and they decide that they have a disability or that they meet, you know, eligibility or something like that. Our effort was to try to make sure that we had enough information that the person could verify it, you know, enough to be able to basically withstand scrutiny if somebody questioned what the assessment came out to be. [LR283]

SENATOR STUTHMAN: The thing that also concerned me is the dollar amount of support service could weigh heavily upon the individual taking the assessment as how he weighted all of these factors, right? [LR283]

DON SEVERANCE: It should be based on what the person's abilities are, regardless of what kind of services they're receiving right now. Should be based on what they have the ability to do or not do would be how the instrument would be scored. [LR283]

SENATOR STUTHMAN: Okay, thank you. [LR283]

SENATOR LATHROP: I'd like to ask some questions, and maybe it will help clarify what I understand or what I think the process is like. [LR283]

DON SEVERANCE: Okay. [LR283]

SENATOR LATHROP: And maybe we can do that by talking about a hypothetical person wanting a particular service and let's say that, you know, I have a son or a daughter who's now 30. She's lived with me at home, and I think it's time for her to have a different situation. And so I come to the department and ask for services. And let's say that we're looking for a residential placement and community-based care is what's going to happen. You will then take my request and some service, assuming there's availability and we're not caught up in that. You will have two people assess this person to determine what their strengths and their disabilities are because the more profound their disability the more reimbursement the community-based provider deserves. That's essentially the premise, am I right? [LR283]

DON SEVERANCE: That's correct. [LR283]

SENATOR LATHROP: And the more abilities that they have the less compensation they

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should receive for the services provided to that particular patient or individual. [LR283]

DON SEVERANCE: That's correct. [LR283]

SENATOR LATHROP: You do the assessment and you look for the level of disability at various functions so that you can add the sum of the needs, and that will give the community-based provider some idea of how much care they're going to have to provide to that person? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: And the amount of care, or the amount of compensation for the care provided is going to correspond to the amount of care required? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: The more high needs that person is, the more compensation they'll get for having them under their care. [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: The assessment is to identify the needs and the strengths so that you can figure out what's fair compensation for the person that's going to take that individual in and provide care? [LR283]

DON SEVERANCE: That's correct. [LR283]

SENATOR LATHROP: The assessments are done not just in conversation, but on objective criteria? [LR283]

DON SEVERANCE: Yes, I'm... [LR283]

SENATOR LATHROP: There's something subjective about it... [LR283]

DON SEVERANCE: Sure. [LR283]

SENATOR LATHROP: ...because one person may or may not agree that a person has a particular need or a deficit. But generally, there will be a checklist that your assessors go through to determine their level of disability in a number of different areas. [LR283]

DON SEVERANCE: That's correct. [LR283]

SENATOR LATHROP: That goes into the formula and the formula then decides how

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many units of compensation will follow that patient into a community program. [LR283]

DON SEVERANCE: That's good, yes. [LR283]

SENATOR LATHROP: That about it? [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: Okay. [LR283]

JOHN WYVILL: And, Senator, we just handed out a flow chart that will just help crystallize the process using a hypothetical client. There's a couple of things that I would want to work out or point out to you. When you determine eligibility, when you determine eligibility for services, then they do an ICAP, it's completed by service coordination. Then it is scored. Then the funding units are determined. When you hear testimony later on from the providers, that determines the number of units, and that's where the providers are saying that the rate methodology, which is separate and apart from the OAP process, they need either more funds or we need to address the rate methodology. So the two issues, when you're dealing with the OAP process, that the OAP process is for units of service for the client, and then the weight methodology that is built in. Because once we determine how many units they get, automatically that determines the weight, and that creates...that creates a situation. So when you have a situation in which a client is currently with available resources, if we talk about a client feels or a parent feels that there are too little resources allocated to them, then they go through the appeals process. In effect what they're saying is, number one, we are not correct; number two, basically, you need to take services away from somebody else to provide services for me. So it's a continuum in terms of we have a finite set of money out there in how we distribute it back and forth. And that's just a little background for you. [LR283]

SENATOR LATHROP: Okay. Senator Wallman. [LR283]

SENATOR WALLMAN: Go ahead and have Senator Gay first. [LR283]

SENATOR LATHROP: All right, Senator Gay. [LR283]

SENATOR GAY: Thank you. I guess on this assessment method, I was just kind of glancing through here, and 17 states use this method? Is that what it says on this little sheet? [LR283]

DON SEVERANCE: Yeah. Yes. [LR283]

SENATOR GAY: And then this was started in '99, 2002, so it's relatively new, isn't it?

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[LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR GAY: What are the other states using then? I mean, this does look fairly...well, it looks complex to us because we don't deal in this every day. But just looking at all these weights, what do other states do? I mean, is there another method out there? Are there three methods? [LR283]

DON SEVERANCE: Yeah. There's quite a few states are using kind of a comparable method to what we did. You know, I mean, it's tailored to each state because realistically, in order to develop those formulas, I had to look at current utilization of services. And what you're trying to do is predict, based on all of these factors, you know, so that you can come up with a formula that will give you what people are actually using, so that you can go forward with it. So each state varies somewhat in their mix, their kind of services and things like that. So they don't end up with exactly the same formula. [LR283]

JOHN WYVILL: And, Senator Gay, if I might follow up, and, Don, correct me if I'm wrong, is that the OAP process that we use has be set forth to us by legislation. And this OAP process, obviously, is a sore spot among some advocates and some family members. And we have met periodically with providers and also with individuals. And then we have...I always ask the rhetorical question, is there a better process out there to see? And we have not been pointed to another state. We have gotten some allusion to maybe looking at Minnesota. But that's the extent of it. So it's a question of trying to get fairness and equity. And, you know, we are certainly obviously open to better ways to do it and improve on it. [LR283]

SENATOR GAY: So to follow up, I understand that you need something that's going to give you an accurate, fair measuring process. I understand that. But when you say this was legislation made you use this formula? The Legislature passed legislation or... [LR283]

DON SEVERANCE: No, it just...legislation said we had to have an objective assessment process. [LR283]

SENATOR GAY: Oh. But then somebody in the...ultimately chose this... [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR GAY: ...and said this is the latest and greatest probably at that point. [LR283]

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DON SEVERANCE: Yes. [LR283]

SENATOR GAY: But you constantly review these things and you look back. But so right now are you actively looking at another method that's a little...that maybe other people can agree on, or are you just kind of...Minnesota? [LR283]

JOHN WYVILL: We are...we have just recently settled the Bill M. lawsuit. And the Bill M. lawsuit was dealing with a variety of things that dealt with weight methodology, notification of clients for the appeal process, and the objective assessment process. Basically, the settlement was that when we go through the objective assessment process to go forward with a new one is that we would include more people at the table, so to speak. And that's the process that there's been some criticism in the past that not everyone...everyone did not feel included in the process. So there seemed to be a sense that did connect out there that there was not appropriate (inaudible). There's always...you're not going to make everyone happy, but then there were some people fundamentally saying we were not even at the table. [LR283]

SENATOR GAY: So are you saying in the future you're going to go look around for a different method and include more people in the decision-making process, more stakeholders, let's say, or whatever? [LR283]

JOHN WYVILL: Yes. Yeah, we're definitely looking at it and seeing what...if there's a better way to do it, we're certainly going to be doing that. [LR283]

SENATOR GAY: Okay, thank you. [LR283]

SENATOR LATHROP: Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Yes, John, in regard to assessments, I've sat through assessments in a different state for a person. And you sit down like with a psychologist, medical doctor, various...an educator, about four or five people. Do we have that same scenario here? [LR283]

DON SEVERANCE: Now, generally, because a lot of people in community services don't have those individuals that know them that well all the time, they're generally actually interviewing the direct care staff that work with the person, both on the day shift and in the evenings, you know, parents, if they're still involved, you know, and anybody else that would have a significant role in the person's life. Those are the people that we're interviewing most of the time, basically, because they're the people that know the person's skills the best, are the ones that are around them most of the time. [LR283]

SENATOR WALLMAN: So very seldom a psychiatrist or psychologist, huh? [LR283]

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DON SEVERANCE: Very seldom. [LR283]

SENATOR WALLMAN: Okay. Thank you. [LR283]

DON SEVERANCE: Yeah. [LR283]

JOHN WYVILL: And, Senator, I want to follow up with Senator Gay. This is just an example, I don't want to bury you with a handout. But this is an example of a spectrum of services that various clients have had. Any time that you tinker with the OAP process, that is going to create a very anxious family and friends because you're talking about individuals that if they get reassessed could move down and then people move up when you're talking about certain resources. So when we do that, that will be very controversial or very upsetting to the families because that will be used for services. And then there could be a possibility of them getting readjusted, and obviously that's not going to sit well if we go that route. [LR283]

SENATOR GAY: Yeah that makes sense. Just to follow up then. Earlier this morning when I asked you about this list, this waiting list that's out there, and I didn't...the answer you gave as best you could at that point, but...so all these things factor into that. You got to run them through this assessment really... [LR283]

DON SEVERANCE: Um-hum. Yes. [LR283]

SENATOR GAY: ...before you can say, you're going to be eligible for these programs. So you can't just change this thing overnight. So what you're saying then is you go through all these, they get an index number, and that creates the eligibility requirements for the programs, or no? [LR283]

DON SEVERANCE: No. No, the eligibility for the program is totally different. [LR283]

SENATOR GAY: Okay. [LR283]

DON SEVERANCE: These are the formulas that say how much service you would get within like a day program, or how much service you would get within a residential program. [LR283]

SENATOR GAY: Okay. But in a way, though, if you're saying, here's what you're going to get, kind of qualifies you, well, this program doesn't serve that type of person. So in a way they kind of work together, don't they? [LR283]

DON SEVERANCE: It could limit your options within those, yes. [LR283]

SENATOR GAY: So I guess the reason I was kind of saying you couldn't quite directly

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answer that question, now I can see why, because there's a lot of factors involved in that. It's not a simple, well, you go here, you go here. You got to look at all these things. So this is a fairly complex way to gauge that. But, I guess, if that's the fairest thing you've found so far, that's what we're going to use for a while, huh? [LR283]

DON SEVERANCE: That's where we're at. [LR283]

SENATOR GAY: Yeah. [LR283]

JOHN WYVILL: However, in your questioning, Senator, you did raise a very good point about the waiting list, about from a wish list, to paring that down. And we've already had conversations in our office about how to address that. So appreciate your point. [LR283]

SENATOR GAY: So you are working on that. That's good. [LR283]

JOHN WYVILL: We're going to start working on it. [LR283]

SENATOR GAY: Thanks. [LR283]

SENATOR LATHROP: If I may, this assessment process is important to two people. One is it's important to the provider that's going to take this person in. Am I right? [LR283]

JOHN WYVILL: Correct. [LR283]

SENATOR LATHROP: And they're going to look at it and say, you've just assessed this person and understated their needs. And so I'm going to be doing a lot more with this particular person that's going to come into my care than what I'm going to be compensated for. So that would be the first rub with the formula. [LR283]

JOHN WYVILL: Senator, you're dead on, on that one. And usually what happens is the provider may come back and say, I can't serve you with those units; I would suggest you either find another provider, or you need to appeal this so we can get you more money. And usually the provider is very helpful with the client because they care about the clients too and want to serve them. But it...ultimately they got to be paid for the services. [LR283]

SENATOR LATHROP: Okay. And then the other person, potentially, who has a concern about the outcome of this assessment is going to the individual who's going to receive the services. Because after the assessment is over, do we make a list of things this person is eligible for? You say, you can go and get community-based care, but you can get A, B, C, and D. And it looks from our assessment that you can do D, E, and F on your own, so you're not going to get those from us. [LR283]

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DON SEVERANCE: We don't prescribe services. This...it gives you a number of units, so you'll have a number of units of residential services. And the person, you know, with their team goes and decides what services they want with that. [LR283]

SENATOR LATHROP: Well, let me ask this question to better understand it then. Let's say that a person has trouble with spasticity, and one of the things they need is to have physical therapy come in and do range of motion with them, or somebody do range of motion with them. That might be a consideration, I didn't look at all of these, but that might a consideration in the assessment, wouldn't it? [LR283]

DON SEVERANCE: It might be a consideration, but actual physical therapy would be paid off of medical stuff. What our services... [LR283]

SENATOR LATHROP: Maybe it's a poor example then, or I chose a poor subject matter for the example. Are all of these things going to be just general needs that go along with the person, and once they land at the doorstep of the community-based provider they're expected to do everything that person needs that they can't get in a contract setting? [LR283]

DON SEVERANCE: Yeah, the team would sit there and decide what kind of services the person needs and who's going to provide those services, yeah, given the amount of resources they have available to them. [LR283]

SENATOR LATHROP: And if I'm the community-based provider, the rub would be I might be at ENCOR, for example, and say, this guy needs this, but your assessment really hasn't identified that as a need. [LR283]

DON SEVERANCE: I don't think...the assessment, the way it is, just gives you an amount of resources to utilize however you want to. So it really doesn't say what you can have and can't have, I guess, except in the sense that you have like a budget, an individual budget... [LR283]

SENATOR LATHROP: Okay. [LR283]

DON SEVERANCE: ...to spend. [LR283]

SENATOR LATHROP: Okay. I think I understand it. [LR283]

DON SEVERANCE: Okay. [LR283]

SENATOR LATHROP: And I appreciate your answers. Senator Gay. [LR283]

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SENATOR GAY: So what Senator Lathrop is talking about, the assessment and you going through there, it still has...the provider has to say we want the patient. I mean, don't they? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR GAY: This has to be a win-win situation in all cases,... [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR GAY: ...which is lots of times hard to achieve. [LR283]

JOHN WYVILL: And there are numerous circumstances, which I'm sure the providers will tell you,... [LR283]

SENATOR GAY: Right. [LR283]

JOHN WYVILL: ...where they fire their clients... [LR283]

SENATOR GAY: Right, because they are saying... [LR283]

JOHN WYVILL: ...for a variety of different reasons. [LR283]

SENATOR GAY: ...your indexing was wrong; we're providing way more than we bargained for in this case; we can't continue to do that. Which is business practices, you just can't. I understand that. But basically it's always last call is up to the provider to say, all right, we'll take the patient. But then they can send them back if it's not working out? [LR283]

JOHN WYVILL: Well, what they have is a...they have a 60-day notice provision in the contract, which they notify you of the intent to discharge them within 60 days. And that means service coordination has to work and try and find, and that's usually a warning signal that there's some other issue, like behavioral health or some other issues that come up. And then maybe it wasn't a good match or there's other issues and then you have to... [LR283]

SENATOR GAY: And that client is back on the waiting list again. [LR283]

JOHN WYVILL: No, we'd be finding another provider. [LR283]

SENATOR GAY: Oh, okay, so you're really off the list and... [LR283]

JOHN WYVILL: Now what could... [LR283]

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SENATOR GAY: ...caught in flux. [LR283]

JOHN WYVILL: ...a typical scenario, not an unusual scenario, could be that a client is with a provider, and then may have a behavioral health episode that gets them into a Crisis Center. And then the Crisis Center is ready for discharge, and then the provider may say, no, I don't think so, or...and then it becomes a...the clock is ticking as to where they need to go. And they come back home, and the mother says or the family member says, I can't handle this client with the behavioral issues. And then they become...service coordination has to figure out, sometimes fairly quickly, where they need to be placed. That's just a hypothetical that happens unfortunately more often than you think. [LR283]

SENATOR GAY: Yeah, it could happen. There's probably a lot of those. [LR283]

SENATOR LATHROP: Senator Adams. [LR283]

SENATOR ADAMS: So clear up for me, and I think I've got it now. I heard it said, when we took our trip to Beatrice, by one of the group leaders and I heard it said yesterday that one of the advantages that private providers have is they get to cherry-pick. Well, to me, using that language kind of takes on a negative connotation. But it would seem to me that this assessment process is what you'd want to look at to determine whether you can provide the proper services for that person or we can't. Am I thinking correctly? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR ADAMS: Rather than cherry-picking... [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR ADAMS: ...and they get the good guys and we don't. [LR283]

JOHN WYVILL: Yeah, it's kind of like a marriage. It's a relationship between or a contract with a relationship between two parties to help out the one individual. And there has to be a good match. And during portions of it there could be change of circumstances or events that necessitate the divorce, a separation, a trial period, or whatever. At the risk of oversimplifying it, though, it's a very fluid and constant thing, and also can be quite stressful for family members and service coordination staff that work with this. [LR283]

SENATOR ADAMS: I see that. So there is something more complicated than the state aid to schools formula. (Laughter) [LR283]

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SENATOR LATHROP: I think that it's analogous. [LR283]

SENATOR GAY: I don't know. [LR283]

SENATOR ADAMS: So I don't want to hear any more about that state aid formula. All right. [LR283]

SENATOR LATHROP: Are there any other questions about the formula; financing, anything on that order? Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Do two individuals ever come up with different figures at the end of the...when you do the formula? Or do they...pretty well your assessment and the factors that are all used, the plus and the minuses and everything like that, do you generally come up with the same answer as far as what type of...or how much funding they get? [LR283]

DON SEVERANCE: No, you get quite a variety of levels of funding, again, based on what a person's abilities are. So...and even a person, over time, changes sometimes. So, you know, with a reassessment, when anybody is new to services, we reassess them after six months even, just because we know the person better after six months, and we get a more accurate measure. And so it can... [LR283]

SENATOR STUTHMAN: So you spend a day on going over the reassessment again in six months. [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR STUTHMAN: And then that could vary amount for the dollars of support for this individual? [LR283]

DON SEVERANCE: Yes, yes. [LR283]

SENATOR STUTHMAN: It could go up or down then. [LR283]

DON SEVERANCE: Yeah, depends on how... [LR283]

SENATOR STUTHMAN: Does that happen very often? [LR283]

DON SEVERANCE: It happens often enough, and especially it seems like with children it's more likely to happen, to tell you the truth. You know, sometimes it's because they're moving from a less stable environment to where they actually ended up with quite a bit of money as far as support. And once they're in services for six months, then the

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stability of the services, a lot of their behaviors improve and their abilities go up, and it will drop the amount they get. And sometimes it's the opposite way around. And part of the reason with children, I think, is because there isn't as many people that know them all the time. So sometimes you have a harder time doing a good assessment at the beginning. So... [LR283]

SENATOR STUTHMAN: So the private or the community-based setting, the one that's providing this service, he has no guarantee that he's going to get the same amount of dollars for this individual in six months as he did two months ago, or five months ago, or when you reevaluate them? [LR283]

DON SEVERANCE: For people new in services that's true, you know. After that six-month period at this point we don't do the reassessment unless they are a priority, you know, and then we would do the reassessment because it would come up that they've got increased needs. And then they're going to get increased funding with a reassessment, most likely. [LR283]

SENATOR STUTHMAN: But there is a chance that they may develop the expertise or the intelligence, with the therapy, that they could receive less funding, too, right? [LR283]

DON SEVERANCE: Yes, that's correct, yeah. [LR283]

SENATOR STUTHMAN: Okay. Thank you. [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: Any other questions? Okay. Thank you. I'm going to, if the commission doesn't mind, I'd like to call one more person up to testify, and that's Mr. Brinker, who's with ENCOR, in Omaha. And the purpose of that would be just to have him give us kind of a view of or an example of a community-based provider. I happen to have toured ENCOR last summer, and it might be useful in terms of our background. Is that all right? [LR283]

SENATOR ADAMS: Sure. [LR283]

SENATOR LATHROP: Everybody okay with that? So he didn't know that he was going to testify until about 30 seconds ago, so... [LR283]

SENATOR GAY: Is he going to talk about residential housing and work programs as well? [LR283]

SENATOR LATHROP: Right, right. [LR283]

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BOB BRINKER: Good afternoon, senators. My name is Bob Brinker. I'm the director of ENCOR. ENCOR serves approximately 800 people in eastern Nebraska, counties of Dodge, Washington, Cass, Sarpy, and Douglas. A little bit about my background: I've been with the agency since 1974, and have been director of the agency since 2004. It's my understanding my charge or the interest is to talk about community-based services that ENCOR provides. And what we provide is similar to what's provided by other providers across the state. We're probably more similar than dissimilar. We each have different takes and different ideas, but in the end we're providing community-based services for persons with disabilities. I think it's important to note that the state of Nebraska was a leader in the development of community-based services for those with disabilities back in the late sixties and into the seventies. People would come across the country to look at services in the state of Nebraska. ENCOR personally has hosted tours from New Zealand, Great Britain, Japan, most recently Russia. We had two very interesting tours from Russia. One was a group of doctors, and the other was a woman's leadership caucus. And the reason I bring that up is just to let you know that the services for community-based, the impetus, the history, the heritage of community-based services was born right here in Nebraska. I think that's something we shall be proud of, and that the Legislature has helped to promote and maintain, through funding and different initiatives over the years. As far as the services that we provide, there's a variety of those services. A lot of talk has been made about group homes. I operate approximately 55 group homes in the greater Omaha area, 40 of those are owned by the agency or rented, 15 the people actually in services sign the lease on those properties. In the group homes I would have anywhere from three to six people, with all ranges of disabilities. People with severe, profound disabilities, the types of activities would be most centered around self-help, self-care type activities, habilitative-type activities. And most importantly, regardless of the disability, to provide for opportunities for integration with the communities, and specifically with their families. One of the things with community-based services, it's services in the community rather than an institution, such as Beatrice, being closer to home, their parents, their family, there's more opportunity for interaction and experiences in the community to do the things that you or I would do as members of communities and things we do with our families, whether it be celebrating birthdays, in the case of Omaha--going to the College World Series. We have a bunch of people that have got tickets, they've gone to the series and they enjoy it. And there's a lot of opportunity for community interaction in fulfilling their wishes and desires as people. And so in the group homes we also have people that are more mildly handicapped. In those situations we might look at more self-development activities in terms of balancing a checkbook, teaching them cooking skills, being independent. And then along those lines we have support residential services. And these are people who are in their own home or apartment by themselves with maybe two or three other people; may have a job, most likely do, could be a shelter workshop, which I'll talk about in a second, could be in a job in their own, excuse me, a job in the community where they're being paid. In those kinds of activities, we send staff

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in on an intermittent basis. Kinds of things we'd be making sure that their checkbook is balanced, they're getting out to do the things that they need to do--going to doctors' appointments, being sure they get into work, and providing the supports that they need, that they say they need and would like and do the things with them that they like to have done. And that's providing support, so we're not providing services by deficit, we're providing supports to people. And that's a very important part of our program. One quick aside I'd like to mention, too, in the early eighties the Legislature approved, it was known at the time as LB033-035 funds. And those funds were specifically for the deinstitutionalization, approved by the Legislature. The consent decree, as Mr. Mason testified to yesterday, was in play at the time. And at that time we as providers were able to go down to Beatrice, screen some people, and prepare a plan of services where we'd identify staffing, startup costs, training needs for the staff. And then we'd bring people into the community. And we did that with several people. One of the stories I like to tell, we had a gentleman that came to us from Beatrice in a total care situation. He moved into one of our group homes, worked in a shelter workshop. And then over time we recognized his skills and abilities. He had those skills and abilities all along. And then he went into his own apartment, which he is today. He shares an apartment with two other guys, split rent and utilities, and doing the things which he likes to do in the community, which is Nebraska football and professional wrestling. And he also works in the community. He does not shelter workshop anymore. He has a job. And I think it's important to note in this case the gentleman was using a lot of tax dollars in the services provided both at Beatrice and initially at our agency, and is now a taxpayer. I think it's important to note that, too. So that's part of the support of residential services. I know I took a long way to get to that point, but I think it's a good example to show the capabilities and the possibilities for people with disabilities when given that opportunity. In our vocational program we have the workshop settings. I have five principal ones, excuse me, five principal ones in the five county areas that we serve. We do job placements for people. People who are on the job, we support them based on what their needs are. Then I also have a very unique program which we call Workstation Industries, where it's kind of a step between a job placement situation and a shelter workshop situation. We're at Lozier's on two of the plant locations, Valmont, to name a few, where we actually have persons with disabilities on the job site, doing the production for the business with an ENCOR staff present. We have a contractual relationship. And those situations have turned out to be quite well and have been quite beneficial for all involved there--the business, the agency, most importantly the persons with disabilities. They earn some pretty good paychecks in those situations too. So anyway, that's a brief overview. We also do some in-home services to persons...to families with persons with disabilities. We provide respite services, intermittent care, could be a weekend when they needed a break, could be a week when the person...the primary caregiver has medical issues. For whatever reason, if they need respite I have a group home that's dedicated to that purpose. And I have a number of providers in the community that we provide services through where they take somebody into their own private home. And we tend to save the group home for persons with more behavioral

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needs, or severe disabilities too. Nonetheless, we provide that service. I also have a very specialized program, it's called the Medical Support Unit, which is unique, where I have nurses at a group home and those nurses handle sophisticated medical needs, among which is like trachea care. I do have other people that are placed in the group homes where I don't have the nurses, that do have G tubes and other medical conditions that can be served quite successfully in the community. I do serve in the group homes a number of people with behavioral difficulties. Many years ago an example of this when the funding was a whole lot different, the situation was back then we'd get a chunk of money and we'd do with it as we see fit. Up until '92, the agency was a caretaker of the waiting list, and then in '92 the state took over the caretaker waiting list. In that situation we had a parent in Cass County who had a son with severe disabilities and severe behavior problems. At that time the agency took the initiative to develop a set of services designed specifically for him. And what that meant at that time was we started a group home just for that person. There was talk, discussion, I think, Senator Cornett, you talk about staffing with two, three people, one person. Well, this person fit that category. And we served that person for an extended period of time in that house by himself. He had severe behavior problems, was endangering other people, potential, so we had to be careful; we couldn't put vulnerable people in there. And worked through a lot of problems with that person. And I'm pleased to report after several years that that person is still in a group home with three or four other roommates, still has some behaviors, they still cycle through, we still have to work through those behaviors. But he's with other people in an environment which is more easily, excuse me, in which we can much easily deal with the behaviors. He attends a day program as well, so he's not in an isolated situation. But it just shows an example of how somebody with severe behavioral issues can be served in the community when given the opportunity and the ability to do so within the community. So that's an overview of the services as I understand what the interest of the committee is. [LR283]

SENATOR LATHROP: That was, and I appreciate...that was very helpful to me at least. Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Bob, you stated you're in five counties? [LR283]

BOB BRINKER: Yes, sir. [LR283]

SENATOR STUTHMAN: Are those in the eastern part of the state, the more populated counties? [LR283]

BOB BRINKER: Dodge, Washington, Cass, Sarpy, and Douglas. [LR283]

SENATOR STUTHMAN: And in Douglas. Have you ever had any interest in going out into the rural areas further? [LR283]

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BOB BRINKER: We do serve...outside those five counties we have not. The way we're set up, we're a public provider. The five counties that we operate, each of the counties has a commissioner or supervisor that serves on our governing board. So our charge responsibility is to those five counties. Now I do have services in Plattsmouth, Papillion, Blair, and Fremont, still in eastern Nebraska, but we do provide services in those cities, both residential as well as vocational. [LR283]

SENATOR STUTHMAN: This is the reason that I asked that question, because you know going to a community-based service and in the more heavily populated areas, you know, there is service provided closer to the people. You know, we have the problem out in the rural areas, where I'm from, you know, where there's a community service provider might still be 150 miles away. And it's really not bringing the person back to the community; it brings them just to another part of the state. [LR283]

BOB BRINKER: Yeah, I understand the challenge. I have the benefit of the population, and also frankly the resources, too. There a lot in Omaha that we're able to use people in terms of therapy services--speech, occupational, physical therapy and the like. There's a lot of availability of those services and I'm fortunate in that regard. The challenge, as I understand it, I worry about transportation costs, trying to get to and from...I can only imagine when the distances aren't tens of miles but hundreds of miles, you know, excessive. [LR283]

SENATOR STUTHMAN: Yes, and that is a problem that we face out in the rural areas, you know, getting providers and then having enough clients, and then having people to come in and work with them, like psychiatrists or anybody like that, you know. So it's two different situations because of our state. We got the population in one area, and we need services out there in the rural area also. I mean we need to provide that, too, but it's a real...it's another issue. And I don't know how we can overcome that. Thank you for your comments. [LR283]

BOB BRINKER: Yes, sir. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Bob, when you decide who's going into a group home or you're going to put a group home together, how do you base your three or four--obviously guys with guys and girls with girls--but how do you prioritize that, who's going into a home together? [LR283]

BOB BRINKER: There's a lot that goes into that. Admittedly, in the early days, if you start working a group home and the agencies, the agency I should say, we'd have space and we'd bring somebody in. And that's the way it was. We'd have a six-bed

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group home, typically, two persons to a bedroom. As time has gone on, as service philosophy has matured, we look at things a lot differently these days. We look at private bedrooms versus two people, as you and I would want our own bedroom, unless we're married obviously. But if you're an unmarried adult, you're probably looking for your own room, so that's the more preferred, humane, proper way to provide services to a person with...so that's part of the consideration. So we have to find housing that would allow for that. Admittedly, I still have houses that have...we take the largest bedroom, the master, and have two people in it. But wherever possible, we sure like to have single beds, one person to a bedroom. Also, a thing that we look at now that we didn't look at years ago is what does a person with a disability have to say; what does their family have to say; who do they want to live with; where do they want to live and that kind thing. So we take that into account as well. Then for my side of the table, a big component of that is looking at compatibility as it relates to, frankly, behavioral issues. In other words, I have to be careful that I don't have somebody with significant behavior problems that manifests in some aggressive behavior in a house with somebody that's vulnerable, like in a wheelchair. So you have to be cognizant of that fact in terms of not only abilities but, more importantly, who wants what and behaviors too. We do, for the most part, separate the sexes, but I must admit I do have a couple houses that are coed, which aren't a problem. Boys and girls don't get together; sex isn't an issue. That's just the way it is. But for the most part, we do have male, we do have female houses, but we do have a couple coed ones too. [LR283]

SENATOR GAY: So in a...let's say Senator Stuthman was talking about a rural setting, but we do have population centers. Are these...are there homes out in Grand Island and Scottsbluff? I mean, isn't there other regions doing the same thing you're doing in different areas? [LR283]

BOB BRINKER: Right. It's my understanding, and I've toured some other providers in other locations. I admit I haven't been out to western Nebraska to tour their services, but this community-based movement, that what's going on Omaha, Nebraska, is going on in other communities across the state; whether it's Omaha, Scottsbluff, parts in between, that that same type of services we provide, may be a little bit different, every body has their own twist, but in the end we're essentially the same. We're regulated and funded the same way and we all have similar interests, and that's providing community-based services to persons with disability in the community. [LR283]

SENATOR GAY: Thanks. [LR283]

SENATOR LATHROP: Senator Adams. [LR283]

SENATOR ADAMS: A second ago you said you're regulated the same way. Can you tell me about, from a private provider standpoint, what your...what the oversight is on the services that you provide? [LR283]

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BOB BRINKER: Sure. As far as the oversight goes, there's an internal mechanism. We have our own quality assurance plan. There's things that we do and activities. There's things that we expect our supervisors to do, and there's things we expect their supervisors to do in terms of monitoring that quality, and we have those expectations. We have outside points of monitoring from parents. It's not necessarily that they're supervisor of the house, but if there's something wrong in there because they're in the community, in all probability, with their son or daughter, they're right there and they can know and be in a lot better position to say what's going right, what's going wrong. And so my supervisors, myself, if there's a problem we can get a call and say this isn't working out or this needs to be done. So there's that component. I do have an advisory committee that provides me feedback to issues affecting the agency. I have a Human League of Rights Committee that also can provide similar feedback to us. And then as far as the outside monitoring regulation goes, as previously testified, we have certification reviews. Certification is granted from a one- to a two-year basis and then at the end of the certification period the state comes back out, checks our services, checks our records. They talk to the people in the services on a sample basis, they talk to their parents, and then at the end of the day they decide whether or not to certify us and, if so, for a one- to two-year period. In the case of ENCOR, they've taken me, and I'm broken into six areas, such a big agency it's kind of like in sixths. It's not exactly that way, but that's what it is, and that goes on. Then additionally, as was previously testified, there's a group of state staff called service coordinators and they come out, look at the residences, look at the day programs and they evaluate us against a set of criteria. They got a form. And then if there's some problems or issues with the form...or, excuse me, problems which are identified as immediate/critical, they'll call. We'll get the form back and we'll be able to respond to it and provide a plan of correction, if you will, and say how we're going to do it. Occasionally, we'll disagree, but essentially we agree with most things that are said and work to correct the problems that may be identified, and that's service coordination, monitoring, review. [LR283]

SENATOR ADAMS: Thank you. [LR283]

SENATOR LATHROP: Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Yeah, thank you for being here, Bob. [LR283]

BOB BRINKER: Yes, sir. [LR283]

SENATOR WALLMAN: Just a couple questions. Do you use the state's assessments and, you know, as far as accepting a person in a group home? [LR283]

BOB BRINKER: No. [LR283]

SENATOR WALLMAN: Or do you use your own assessments? [LR283]

BOB BRINKER: We don't. Internally, we have our own assessment tool. State assessment is what gets the money. You know, at the end of the day, that's...we'll give you this amount of money. And then it's the agency's own process, we'll do an assessment of that person's need. Now we have an in-house tool that we've used, as well as we've moved over time to more progressive measures of seeing what people need too. In addition to taking a look at what they don't have, in current contemporary service, I...let's take a look at what the person needs and what they want, and what their parents say they want, too, and taking a look at that. But after everything is said and done, when you have a service decision, it's amount of monies on the table, if you will. That's what it comes down to. And I got to take it...we got to look at it and say, okay, can we serve this person within the parameters of what we have available at the time and the day that that question is asked. With these different facilities that I operate, I may have an opening at a location one day and someplace else the next, and so the day I get the referral, if you will, and the day we...in subsequently, do our assessment, we make a decision on whether or not to serve the person based on those issues as well as where that, physically, where that opening is at that time and who else is in that environment as well. So we make our own decisions based on our own rationales. [LR283]

SENATOR WALLMAN: Question number two: As far as sheltered workshops, what percentage of your clients work in a sheltered workshop? Do you have trouble getting jobs or...? [LR283]

BOB BRINKER: We have, of the total people we serve in our day services, I probably have, rounding, just off the top of my head, I probably have two-thirds, 70 percent, and I'm just doing it off the top of my head. I know, I can give you some numbers. We work with 60 people, approximately, on the job site and those Workstation programs, with Lozier, Valmont. We send people in the actual business with ENCOR, I have 40 people, like, in that program. Then I also have a unique program we run as a recycling program which we recycle paper. I have 40 people placed in that. And then beyond that we have people in the day programs. One thing I should point out, too, in our day programs and our work shelter workshops, I do have some very specialized programs within those workshops. I have a couple that serve persons with severe/profound orthopedic disabilities. And then of those two programs I have one that not only have that but have particular medical needs where I have a nurse present at all times. Several of those people have "trachs," which you need to have a nurse there too. So I have a spectrum, if you will, of different types of services in the shelter workshop. My point is that we've significantly...people with significant impairments at those locations and, unfortunately, the reality of the situation is any time in the near future the people are going to need very specific qualified care, and, in several cases we need nurses there because of the

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"trach," so... [LR283]

SENATOR WALLMAN: I appreciate that workshop thing because that mental health has a lot of do with work to a lot of adults. So thank you. [LR283]

BOB BRINKER: Yes, sir. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: I, sir, I believe I met you about four years ago,... [LR283]

BOB BRINKER: Correct. [LR283]

SENATOR CORNETT: ...right after I was elected. I came down and toured one of your facilities,... [LR283]

BOB BRINKER: Yes. [LR283]

SENATOR CORNETT: ...and your group homes. At that time, we had a discussion that you needed more...that you did not have enough beds available for all the people that were requesting your services. Is that still true? [LR283]

BOB BRINKER: It comes back... [LR283]

SENATOR CORNETT: Well, not beds, but home,... [LR283]

BOB BRINKER: Right. [LR283]

SENATOR CORNETT: ...residential living. [LR283]

BOB BRINKER: It comes back to the issue of the waiting list. It was previously testified that the needs are many and the resources are few, if you will. And so in terms of services, at this point in time it's continuation of services and that if the needs are going to be met to those persons on the waiting lists that we would need to increase capacity, which would include residential situations such as group homes. [LR283]

SENATOR CORNETT: What would that lag time be? I mean if we were able to fund the list, how long would it take you to get your services up to the number of people that we funded? [LR283]

BOB BRINKER: If everybody on the waiting list was...? [LR283]

SENATOR CORNETT: No, not...just... [LR283]

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BOB BRINKER: Okay. [LR283]

SENATOR CORNETT: How long would it take you to expand your services? Because you would have to buy homes, retrofit them. [LR283]

BOB BRINKER: Right. It could take...a simple example, say if money became available to serve three people off the waiting list who needed a group home, simple example, from the point of notification it would take us anywhere from three, maybe six months. And there's a lot of variables that go into that time frame, but just to give a ball park based on my best professional estimate, I'd give that time frame. [LR283]

SENATOR CORNETT: I remember you and I had the discussion, and this was years ago, but on the length of time it takes to find a proper location, the neighborhood notification... [LR283]

BOB BRINKER: Right. [LR283]

SENATOR CORNETT: ...and then finding a home that can be converted economically to be handicapped accessible. [LR283]

BOB BRINKER: That's an important point. As one of the things we've gone organizationally as we've aged, as the agency, so have the people we serve or potentially serving, too, frankly, and that I'm more cognizant now than I was 20 years and need to have houses that are wheelchair accessible and need to be made accessible either on an immediate basis right now or some point in the future, too, so I'm looking for ranch-style housing as well. It's become more and more an issue. I'd say out of the last four homes we've located, three out of the four are wheelchair accessible, so that's a big issue and will continue to be at the forefront of our future service development. [LR283]

SENATOR CORNETT: Thank you. [LR283]

BOB BRINKER: Yes, ma'am. [LR283]

SENATOR LATHROP: I do have a few questions, if I can. I do appreciate you willing to step up and share your experience as a community-based provider on very, very short notice. We have talked about Beatrice, that's been the scope of much of what we've talked about, and the placement of people from Beatrice into the community-based setting, and one of the things that we go back to is the safety risk of that placement. You make this judgment all the time about which people to take into your program. I suppose the first question is, is your program a typical program. The way you approach a referral, do you think it's typical of the way other community-based providers approach a

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referral? [LR283]

BOB BRINKER: In my opinion, I would...in my opinion, Senator, we're probably more similar than dissimilar in the end, yes, sir. [LR283]

SENATOR LATHROP: Okay. So I want to ask you some questions. I just want to make sure that there's some universal application to your answers. To what extent...are there some patients or some residents whom you cannot accept into a community-based program for safety reasons? [LR283]

BOB BRINKER: Yeah. [LR283]

SENATOR LATHROP: Can you give us a sense of the people that... [LR283]

BOB BRINKER: Sure. [LR283]

SENATOR LATHROP: ...you'd say we can serve the DD community, but there's some people this isn't suitable for. [LR283]

BOB BRINKER: Right. I have a strong bias, excuse me, bias for community-based services in my heart. I'd like to say we could serve anybody any time, but, to be honest with you, there are certain situations that I would probably stay away from. Earlier there was testimony about the Bridges Program and some people being served there. I'd be very concerned about that, reason for that being that we serve...we have houses in the communities. Their sexual predatory behavior, that's difficult. That's a safety issue and I would think twice about serving that person. Now equally, over a period of time through habilitation and other efforts, hopefully people do better and we could take a look at somebody at a later date if they improve. But if there's a current issue or problem, we would take a look at that very seriously and probably deny placement in certain cases. And that's a small faction, I might add. [LR283]

SENATOR LATHROP: Yeah, and you've given us an example or you've made your point with an example of the...of perhaps the most obvious one and that's the people in the Bridges Program who we can't even keep at Beatrice safely, apparently. But are there people whose behaviors are so aggressive that they might not end up in Bridges but whose behaviors and whose aggressive tendencies are such that you just can't take them? [LR283]

BOB BRINKER: It's possible. I know it's a bad answer and I'd like to expand on that. There are people, as we get through the assessment process ourselves--and there's the ICAP and there's an amount of funding that's available through that ICAP with severe, so I'd have to take a look at what that ICAP has to say--there may be those people that are so aggressive that, regardless of what the ICAP say, that I would give second

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thoughts to. I did mention earlier in my testimony an example of the young man from Cass County that did have aggressive behavior problems and the funding was such and the organization was...structure of the state was different at the time that we did set up a house specifically for them and made progress. But there would be some individuals--highly aggressive behaviors, use of weapons and that kind of thing--that I would give great consideration not to serve because of that. And I, frankly, have to look at it at a case-by-case basis. [LR283]

SENATOR LATHROP: When we toured Beatrice, there was a young man who was working on something and I don't know what his limitations were, but he communicated well. And he told me, I have an interview, which I assume meant that he had an interview with a community-based provider to see if he was a suitable fit. And as we left, somebody that was sponsoring the tour said he's got some aggressive tendencies, we're having a hard time making a fit. That seems to be kind of where the line is when it comes to Beatrice versus the community. [LR283]

BOB BRINKER: That's a significant issue in placement, as we look at...and then as the function of what the funding is too. [LR283]

SENATOR LATHROP: All right. Thanks. Senator Cornett. [LR283]

SENATOR CORNETT: If you have someone, like yesterday we had a doctor testify that they have a young individual that pretty much requires two- or three-on-one care because he has self-destructive behaviors. Are community-based programs ever funded for that level of care where it would take three staff members or two staff members watching that person 24 hours a day, working with behavior modification? [LR283]

BOB BRINKER: I don't know the answer to that question. The referrals that we have, I've not seen anybody with that high level of funding approved, number of hours I'd have to defer to the state on. It's an interesting question, is it, what's under the ICAP, what's the highest amount of hours possible and is that two- or three-to-one, as you...I don't know the answer to that question. [LR283]

SENATOR CORNETT: Because they have people at Beatrice currently that are two, I believe, on one person pretty much 24 hours a day and that I don't know if that would transition to community-based. [LR283]

BOB BRINKER: Yeah, and I don't have an answer to that question. [LR283]

SENATOR LATHROP: Senator Adams. [LR283]

SENATOR ADAMS: Yesterday we heard about the need for occupational therapists,

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speech therapists, psychologists at Beatrice. So how is your community-based program staffed in those skilled professional areas? [LR283]

BOB BRINKER: We have the, as you were talking about earlier, the difference between urban and rural, in eastern Nebraska we have a number of therapy providers--physical, occupation and speech. Those services are paid by Medicaid. The agency doesn't pay or contract that directly. So when we get our amount of service from the ICAP, there's not a factor in for that. That comes from Medicaid directly. And then there's organizations and resources that are used, a couple main ones in Omaha, but there's a variety of ones we use for those different therapies. But I don't have a physical therapist, I don't have a speech therapist, I don't have an occupational therapist on staff. If I go back to ENCOR's history, 30 years ago I did. There's a variety of reasons for that. As time has gone on, funding has developed, federal money came in and so on and so forth. But as it stands now in today's operating environment, that's paid for by Medicaid and not directly on a contract relationship between the agency and the therapy provider. [LR283]

SENATOR LATHROP: I think that's it. [LR283]

BOB BRINKER: Okay. [LR283]

SENATOR LATHROP: Thank you very much. [LR283]

BOB BRINKER: Thank you, Senators. Appreciate the opportunity. [LR283]

SENATOR LATHROP: Thank you very much for your testimony. I believe that concludes our hearing for today, so thank you all for being here. [LR283]

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The Developmental Disabilities Special Investigative Committee met at 9:00 a.m. on Thursday, August 21, 2008, in Room 1524 of the State Capitol, Lincoln, Nebraska, for the purposes of conducting a public hearing the Beatrice State Developmental Center. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Arnie Stuthman; Norm Wallman. Senators absent: Abbie Cornett, Tim Gay. []

SENATOR LATHROP: (Recorder malfunction) Steve Lathrop. I'm the Chair of the commission established by the Legislature by resolution LR283. Our purpose is to investigate the services provided by the state to families and to folks with developmental disabilities. We had hearings in June and we're today having hearings, the purpose of which is to hear from families and those who have an interest in the subject matter, what their perspective is on how the state is providing care and services to people with developmental disabilities in the state of Nebraska. That includes the Beatrice Development Center, of course, but it also includes, and you should feel free to comment, on the care and the services provided with community-based providers. This commission that I'll introduce in just a moment comes from a different...a variety of backgrounds. I happen to be an attorney in Omaha. We have folks that are retired teachers, former school board members, farmers, and bankers. So what we're doing is educating members of the Legislature through this process on developmental disabilities and the services provided by the state, and any shortcomings we may have in the provision of those services and problem areas. So we look forward to your testimony today. I'll start maybe by introducing the folks that are on the commission and that are here today. I have, to my left and your right, Norm Wallman who's from the district that includes the Beatrice Development Center, and he's serving on the commission. Also Greg Adams, who's from York. I'm from the 12th District or in the Omaha area. And then we have Senator Stuthman who's here today from Platte Center, which is basically Columbus, for those of you who might not know where Platte Center is. Also on the commission are Senator Cornett, who has a conflict today; Tim Gay,

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who's from Papillion, also has a conflict; and Senator John Harms from Scottsbluff had a conflict this morning and I think he'll be here this afternoon and tomorrow. We are assisted: our staff today is Beth Otto, who's our clerk; and Doug Koebernick, who's my legislative assistance; and Matt Boever, who is our staff, and that's the guy in the dark suit over there and is working with us today. We have...I really didn't know what kind of a response we'd get today, so I didn't know if we would simply open the mike up, let people sit down and talk as long as they wanted to. But, as you can see, we have an awful lot of people here, which is terrific, and we want to hear what people have to say. Can you, by show of hands, tell me how many of you wish to testify today? Okay. That's good. We're glad you're here and we're interested. Just a couple of thoughts, if I can. I'm going to repeat some of the things that we say in Judiciary Committee, where we have a lot of hearings and a lot of bills that we deal with, and that is you are welcome to submit your testimony, if you like, in writing, if you are bashful about public speaking. That information will be copied and passed around to the committee. When you speak or before you speak you have to fill out a form so that our committee clerk can keep track of who's spoken, you know, get the name right for the record. So we have forms that need to be completed before you testify. You'll put them in the box here and then we can keep track of who's testified and we get your name right in the record. We will ask you, if you can, to listen to what everybody else has to say ahead of you and then if you can avoid repeating the same things so that what we are getting is new information each time somebody testifies. And to...I don't want to, at least initially, to limit people, too, and we don't have the light system today. But if we start going too long, I'll just ask you to kind of try to keep it in the ten-minute range if you would. If we get much past that, I may interrupt you and ask you to wrap it up. The reason we do that is not because we're not interested in what you have to say, but because we won't leave here till 8:00 tonight if we listen to everybody say everything they absolutely want to say. But we do want to give everybody a fair opportunity to speak, and the people behind you that same opportunity. So I think...oh, this is being recorded. You have to speak into the mike. And we also ask that everyone here turn their cell phones off, all right? Cell phones, pagers, what ever that's going to make noise and interrupt the hearing, we'll

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ask you to turn that off, if you wouldn't mind. And then we have no order. I have no slate of speakers. So what we'll do is just say that if you want to speak maybe you come up to the front row and just sort of sit in a chair there and position yourself by completing a form and then we'll just call on the next speaker after we've heard. Today the folks that we hope to hear from are people, families who have loved ones that are getting services for a developmentally disabled member or ward, people who have an interest in it, interest groups, those who have been around the provision of developmental disabilities services long enough to have an idea of how we're doing, what we're doing, what our shortcomings are, and what we're doing that seems to be working. So with that, I think...sign-in sheets, printed materials...if you have printed materials that you want to hand out, you can hand them to our page over here. This young man will pass them out. You don't have to hand them out or leave them on the table. And with that, I think we'll start. Okay, thank you. So our first speaker. []

JOAN O'MEARA: Good morning, senators. []

SENATOR LATHROP: Good morning. []

JOAN O'MEARA: My kids evidently knew that you were going to say this, because they made me put it on cards. They said, don't get long-winded, Mom. []

SENATOR LATHROP: Okay. And what I should say, because I don't know you any more than somebody's mom right now, we'll have you start with give us your name... []

JOAN O'MEARA: I will. []

SENATOR LATHROP: ...and spell your last name for us, and then we'll go from there. []

JOAN O'MEARA: (Exhibit 1) My name is Joan O'Meara, O-'-M-e-a-r-a. I am the mother and guardian of Cindy O'Meara and I'm president of the Family and Friends Association

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of BSDC. I have worked in the field of mental retardation for 54 years, both personally and as a teacher of special education. I am no stranger to the levels and needs of those with MR. Cindy is severely/profoundly retarded. She had open heart surgery, club foot surgery done before she came into the institution. She is blind in one eye, deaf in one ear, and is diabetic and is wheelchair confined. My daughter has been at BSDC for 44 years--a place she calls home. She is happy, safe, and well cared for by dedicated and well-trained staff. There is a doctor, dentist, nurses, dietician, psychiatrist, psychologist, a physical therapist, all on staff. She and I have the right of choice to live at BSDC. The Olmstead decision gives us that right. We are moving people out to reach a number, quote, which is frightening to me. To me, it is like dumping. Many have gone to nursing homes because they are old and not learning. There was a study made a few years back that those put in nursing homes out of familiar environment lasted for only two or three years. Is this what we are doing--pronouncing the death sentence for them? Wouldn't it be humane to let them live their final years in familiar surroundings--their home? We parents have been told that BSDC is a learning institution. I haven't found anything in the papers establishing BSDC that mentions that. Those who favor community programs say that we are isolated. Not true. Cindy has a better social life than I do. She goes to Omaha and the Lincoln zoos, Brownville, football games, car races, movies, out to eat, shopping in Lincoln and Beatrice, parties, barbecues, just to name a few, plus her family visits her often. Some can live in community homes but only if those community homes meet the needs of that individual. Community programs are facing problems just like we are--not enough staff, not enough qualified staff, not enough homes. You need to find your own doctor, dentist, psychologist, etcetera, and that's not an easy task. Most doctors will not take retarded people. Rules and regs are not the same across the state and no one to look over their shoulder. If this were to happen, there would be quite a few homes that would be closed. I spoke to CMS and asked them why they don't visit community homes. Their answer: They are too spread out; it's not realistic for us to do it. So if we transfer a person, we want to make sure that that person is going to a home that is equal to the environment that they have now. But if these environments are not regulated then we have problems. There's a long waiting

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list for community programs and I have a paper here. The numbers are terrible. They need to be also serviced. This, as a list, will grow continuously year after year. Especially when those who are attending high school graduate, they need a place to go. They don't have one. And how would you feel when an opening happens but you are passed over because BSDC has priority needs to reach a number? Some of these parents are up in years and have been on the list for many years, 5 to 14 years. We're robbing Peter to pay Paul in doing this. Some parents have tried community placement and found it fearful and unsafe for their child. They turned to BSDC and found a haven. The whole DD program needs to be revamped from the top on down. Rules and regulations across the state, community, and BSDC must have the same rules, an unbiased overseer is needed to look to see that these rules are followed. And when a change is made, whether it's from BSDC to a community home, that person goes to see that that community home is going to meet the needs. Or even if from one community home to another community home, that, too, has to be supervised so that these people's needs are served. Changes need to start with those at the top. We need qualified, experienced people. Start with listening to the staff. They know what's needed. The direct-care people are not stupid. They've been in the field for many, many years and know what is happening. We need to bring BSDC back to the status of Cadillac among centers, as it was in the 1990s. How can you find out how it was? Ask an old worker who has been there for 30 years. They know what was going on then and what made us good. Why weren't they included in the changes that were made? They weren't. And we spent oodles of money on bringing people in and not to any avail. This committee is the first one to listen to we parents. We have fought for over 15 years, going from the top to the bottom. You finally have heard our voices and you're giving us hope. The right to choice is essential. Thank you for listening. []

SENATOR LATHROP: Thank you. Are there any questions? Senator Adams. []

SENATOR ADAMS: I heard... []

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SENATOR LATHROP: Miss O'Meara. []

JOAN O'MEARA: Excuse me? []

SENATOR ADAMS: Would you be willing to answer? []

JOAN O'MEARA: Oh, I'm sorry. []

SENATOR LATHROP: He wants to ask you a question, if you don't mind. []

JOAN O'MEARA: Oh, sure. Go ahead. I thought I was through. (Laughter) []

SENATOR ADAMS: Well, not with this group. []

JOAN O'MEARA: Oh. Okay. []

SENATOR ADAMS: I have heard it said more than once, and you said it just a moment ago, that in the 1990s we had a Cadillac program and we don't now. Now I've heard what others have said has happened. In your opinion, what's the difference today compared to the 1990s? []

JOAN O'MEARA: We had a very qualified person in charge at BSDC with great experience and really listened to the workers, making themselves visible and asking questions and listening to them was very important. We had people from all over the world coming to our program that we put on in April, I think it was, and they were just amazed. But since then, we have continuously slipped. Our one who was in charge at that time passed away. []

SENATOR ADAMS: Okay. Is there anything else? []

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JOAN O'MEARA: No. []

SENATOR ADAMS: Okay. Thank you. []

JOAN O'MEARA: Any more questions? []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. []

JOAN O'MEARA: Yes. []

SENATOR STUTHMAN: Joan, do you feel that an individual that has a disability is a lot harder to accept move than a normal person? []

JOAN O'MEARA: Oh, oh, yes. Yes. You are disturbing their whole environment, the people that they are around, their fellow peers, and the workers that are there to help them. Yes, I think that they are, especially those who are severely/profounded retarded, and then behavior problems begin to act out, behavior that you have at one time had them contain those behaviors, and now you're switching them again. That upsets them. Look at it this way. When my mother was living with me, she was 91 years old and she had the beginnings of Alzheimer's. If her day was disturbed, like if she didn't have coffee at the right time or she didn't have something that she was supposed to do at the right time, she became very upset, very much so like the people that we're talking about. Now there are some individuals who are mildly retarded, no, that wouldn't. []

SENATOR STUTHMAN: Okay. Thank you very much. []

JOAN O'MEARA: Uh-huh. []

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SENATOR LATHROP: Good insight. Thank you. Our next presenter. []

KATHY HOELL: Senator Lathrop, I'm just going to thank you for letting us have this opportunity. My name is Kathy Hoell, H-o-e-l-l, and many of you do already know me. However, today I am here testifying as an individual, an individual that resided in an institution for two years. Those two years felt like ten years to me. My life back then was extremely depressing. I had no power to decide things for myself. I got the roommate they selected for me. I had to eat when they said I had to eat. I had to eat what they said I had to eat. I couldn't go to the bathroom when I wanted to. I couldn't go to bed when I wanted to. But, however, the one thing that I did learn very well, and it's a word that gets tossed around a lot, is behaviors. I had a roommate who screamed every time she didn't get what she wanted. She screamed loudly. And if she didn't...if that didn't work, she stole things. I learned this behavior. People in institutions learn behaviors from other individuals in the institution. I got to a point where I called my grandparents one night and started screaming at them. These people never did anything to warrant that type of abuse from me. However, my institution was a nursing home. The fact is an institution is an institution is an institution. They've transferred enough number of people out of Beatrice and put them in nursing, so they've just changed the institution. I really do appreciate the enormity of the task you've taken on. However, the disabilities service system in Nebraska is very fragmented. We need to have a unified system and, as Joan was saying before, we need to start at the top and go down. Ideally, what we would have is a division of disability service so all disability services are in one location; there is no wrong door. People are going to get the services they need. We have another problem in Nebraska and that's the DD waiting list, and we have an unofficial behavioral health waiting list and, in my opinion, the only way these are truly going to be dealt with is to make disability services in this state an entitlement where, if you're declared disabled, you get services. Because my fear is this Legislature will throw money at the DD waiting list, because they've had so many years of broken promises, and they're going to make that behavioral health waiting list an official waiting list. And I don't want to see anybody having to wait to get services. In the community, I have a right to go see

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the doctor to choose. I have a right to do what I want to do, go to movies, and everybody deserves that same right. In regards to what Senator Stuthman asked earlier, I've known a lot of people who have come out of institutions over the years, yet they might a little...been a little tentative to be in with, but it's the best thing they ever did. And a lot of them will tell you, they'll go back kicking and screaming; they are not going to go back voluntarily. Because their lives are so much better and so enriched by the people that they meet every single day of their lives. Thank you. And if you have any questions... []

SENATOR LATHROP: All right. Thank you, Kathy. Anyone have questions for Kathy? Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Kathy, thank you for coming and giving us your testimony this morning. Do you feel that if everyone that is...has a disability...you stated that they should all receive services. []

KATHY HOELL: That's right. []

SENATOR STUTHMAN: How are we going to be able to fund all of that, or how is there going to be enough people to provide these services throughout the state of Nebraska and all over? []

KATHY HOELL: The state of Nebraska has neglected the disabilities system for many, many years and we're seeing it now, with the cuts in Medicaid and everything and the problems that are flourishing at BSDC. Nebraska's home- and community-based service system in the DD was the gold standard back in the sixties and seventies, but that's because the state of Nebraska was funding it appropriately. But if the state of Nebraska would rebalance its budget, by rebalancing it I mean take the money that you're throwing at these antiquated institutions, trying to keep them running, and put that money into home and community-based services, we'd have money to adequately pay

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people. And, people, right now you can make more at McDonald's than you can as working at a home care provider. So we've got to figure out a way to rebalance that money, and it can be done. Other states are doing it. Forty-seven states have recently closed their institutions for developmental disabilities. []

SENATOR STUTHMAN: Another question, Kathy, is, you know, we have a waiting list. Do other states have a longer waiting list or are you aware of that? []

KATHY HOELL: Some do. Some do and some don't. The ones that don't are not...they're at the same point that we are. They think by cutting back on the home- and community-based services, which is essentially what we're doing in this state, they are cutting back what people receive. When they don't receive the new supports, they end up going into institutions. We're paying more money to the institutions. []

SENATOR STUTHMAN: Okay. Thank you, Kathy. []

SENATOR LATHROP: Any other questions? I did want to ask you, you said you testified as an individual. Are you here representing any particular group? []

KATHY HOELL: No, I'm not. []

SENATOR LATHROP: Just your own perspective. []

KATHY HOELL: My own personal opinion on all of this. []

SENATOR LATHROP: Very good. []

KATHY HOELL: And I've got an opinion. Just ask anybody that knows me. []

SENATOR LATHROP: Well, we appreciate it and it's good to hear from you. Thank you

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for coming down today. []

MARGARET HUSS: Do I put this in here? []

SENATOR LATHROP: Is that a handout or a...? []

MARGARET HUSS: It is. I only have a couple of them but it's for you guys. I could give it to... []

SENATOR LATHROP: Okay. The best thing to do is put it in the box. Okay. []

BETH OTTO: That would be fine, or he could make copies, too, of some of it. []

MARGARET HUSS: I have a couple extra copies, but I don't think I have enough for everyone. []

BETH OTTO: Yeah, he can make some copies. []

MARGARET HUSS: Good morning. []

SENATOR LATHROP: Good morning. []

MARGARET HUSS: (Exhibit 2) My name is Margaret Huss and I live in Omaha. My last name is H-u-s-s. I grew up in the Florence area with nine siblings, including my brother Clete, who has been a resident at BSDC for over 25 years. Clete has profound, lifelong disabilities. He has a seizure disorder. He's nonverbal. He's considered profoundly retarded. He's been described as functioning at a preschool level. Yet, he is also six feet tall and he's a physically robust man. He needs assistance with each and every activity of daily living. He has received wonderful assistance with basic human needs and much more at Beatrice. My parents chose BSDC for Clete, when he became a young adult, as

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the best of all available options. I know with a certainty borne of experience that this continues to be the case. Cletus receives compassionate care at Beatrice in a homelike environment. He's cared for by people who have known him for years. And he also has many enrichment opportunities at BSDC, more than I think he would ever have in a community-based setting. I'm here on behalf of Cletus and others like him who cannot speak for themselves. My goal is to address some of the commonly held misconceptions in this very complex, emotionally charged area. Because of its complexity, I've also supplemented by brief statements with some authoritative material, which I urge each of you to read at your leisure. I want to thank each of you for the opportunity to speak today. One main misconception is that community placement is always the best option. The reality is that for some high-needs individuals places like BSDC offer the least restrictive environment. A person with mild disabilities who can take a bus to a job at Hy-Vee or Wendy's can have a happy life in a group home setting, but my brother will never be like that. I am happy for those who do thrive in the community, but I know it's not for everyone. At BSDC, however, Cletus does have wonderful opportunities besides just living in a residential cottage. He goes swimming every week at a pool that's there on campus he gets to walk to that's maybe two blocks away across an open field. He loves to be outdoors and at Beatrice there are adult-sized recreation equipment, basically playground equipment. He gets to have access to that on a daily basis. He goes to Mass every Sunday because a priest at...from Beatrice comes out and there's a nice chapel there, and so he gets to participate in that. He's in a walking club on campus. They have three-wheel bicycles there, again built for adults, and that's one of his...you know, he's very happy to be able to do that. Those are just a few of the things that he does, not once a year but every single week, and I think any one of these activities in the community would present a logistical challenge. He'd be in a group home in Omaha. He wouldn't be riding a bicycle on the street. Each one of those activities that he participates in because of the campus setting he would need transportation for, and with each of these things he does need constant assistance from someone. He's not doing this on his own. For those reasons and many more, I think that BSDC is the right place for him. I know that facilities are not

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in vogue. I've never really understood, however, the advocates of the one-size-fits-all approach who sometimes seem uncomfortably delighted with bad news about BSDC making the headlines. And, by the way, one reason there is so much bad news is because facilities like BSDC get lots more scrutiny than do their group home counterparts. This is both a benefit and a burden. As an example, the Department of Justice was able to investigate BSDC pursuant to a federal law called the Civil Rights of Institutionalized Persons Act. This act only applies to persons residing in places like BSDC or nursing homes or prisons. I asked the DOJ attorney who drafted the settlement agreement--his name is Rich Farano--whether there was a statutory scheme that protects the civil rights of those in community settings. He told me he knew of no such laws. Thus, as it stands now, those in prisons have more protections than disabled persons who live in community settings. Does this seem right? When we push high-needs folks out into the community, I'm not sure that no news is good news. Who will advocate for them? Another misconception is that community placement is mandated by the federal government. The reality is that nothing in the Americans with Disabilities Act or the Supreme Court's decision in Olmstead or any other statutory scheme requires community placement. In fact, just the opposite is true and to support this I've provided a letter in the materials I've given to you from the director of Government Relations and Advocacy of the VOR, which is a national advocacy organization. This person is an attorney and the letter was addressed to Nebraska state officials last month and it details the actual state of the law. I urge you to read this if you have not already had an opportunity to do so. The final misconception I wanted to address is that facilities like BSDC are more costly to operate than their community-based counterparts. Again, the reality is far different. The bottom line is that, when all factors are taken into account, savings do not occur when states close institutions and shipped residents to group homes. If the state of Nebraska closed BSDC, taxpayers would not save money. To support this, I've attached a 2003 authoritative article in a peer review journal which looks at cost comparisons and historical research over a 25-year period. The article is 20 pages long, but as policymakers I urge you to read it. It will help you understand the complexities involved

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and may also help avoid making decisions based on fault assumptions that ultimately could result in lower quality of care for our most vulnerable citizens. I would like to ask add that a number of other states have passed or are considering laws that would prevent the closure of state facilities like BSDC except as approved by the state legislature. Such a law in Nebraska would provide increased protections for our most vulnerable citizens because it would empower citizens, via their elected representatives, to have a voice. Such decisions could not then be implemented solely by the executive branch or by appointed administrators. I urge you to consider introducing similar legislation in the Unicameral. There are, as I said, a number of states who have already done this: Ohio, South Carolina, Washington, Oklahoma and others. In closing, I would like to thank you again for your willingness to take on this challenging task. I urge you to do what you can to ensure the ongoing viability of BSDC. It's a good and needed facility. Where there are problems, let's fix them. The community is not for everyone. It comes with long waiting lists, compromised care, and limited safeguards. I believe Nebraskans are sensible people. We know a range of options are necessary and, with your help, we can decide for ourselves what is best for Nebraska. Thank you. []

SENATOR LATHROP: Thank you very much for your testimony. Senator Adams has a question for you. []

SENATOR ADAMS: Thank you, Senator Lathrop. Obviously, from your testimony, you're satisfied with the care at Beatrice, but let me follow up with another question that I had asked an earlier testifier. Have you seen a difference in the quality of care from the nineties to now, and, if so, what might that difference be? []

MARGARET HUSS: I was a young adult when Clete first went there and so my perspective is a little bit narrower than some of the people who have been around much longer. But I think that there have been struggles at BSDC. Places could always be better and I think there have been struggles with staffing, getting...this is very difficult work. As the previous...as Kathy pointed out, some people can make more money at

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Wal-Mart in Beatrice than they can taking care of basic human needs for severely disabled people. So I think that staffing has been an ongoing problem, especially in recent years, of finding and keeping quality staff. And I think that there are very many compassionate people there, but it is very difficult work and that's one thing that I think is a constant grind. And I do agree that there was a wonderful administrator out there who lived on the campus and that helped immensely. Although we call it a facility for the people who live there and their families, BSDC seems like a community, so sometimes I think we're arguing about semantics more than anything. And the community-based programs, of course, also have severe problems with staffing shortages and lack of funding for services. []

SENATOR ADAMS: Thank you. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Margaret, do you have any information or do you have any knowledge of a community-based service that could provide something close to what your brother is receiving? I know you said, you know, they could go swimming, he could do a lot of activities and stuff like that. Is there anything in the state that could provide something close to that? []

MARGARET HUSS: Well, I, as I said, of the options currently available, I still feel that BSDC offers the most rich and best environment for my brother. I do attend, because I try to be as informed as possible--because I'm his guardian and I, like most of us, take that seriously--I go to fairs and I'm fairly familiar with what's going on in the community. If Cletus was to be placed in the community, it would be in Omaha because that's where his home base is. Every year, as part of his annual evaluation, the Eastern Nebraska Office is contacted about his needs and every year we get a letter back saying there's nothing in Omaha that would meet his needs at that time. And when you work with someone who's disabled, you know in your heart that the things he needs and the

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places he would have to go to get them, he'd spend more time in a minivan than he would participating in even one or two of these. And it's while he's doing that, where are the other guys who live with him who also need one-on-one? It just becomes very difficult logistically, and if you thought about it you'd, you know, you can see that that's the case. So right now, no, there's nothing that would provide him as rich a life as he has there. []

SENATOR STUTHMAN: Okay. Thank you. I do want to make two points, if I can. You've provided us with a handout and mentioned that the state would not save money by moving people to community-based care, and you have an article that's in the handout. But if I understand the substance of the article, that is, at Beatrice people receive a variety of services that we'd have to contract for once they move. And so if we're looking at the costs--we have a place for them to stay and all the services at Beatrice and we can take them to a community-based program but then we have to find a doctor and transport them to a doctor and to each one of these services and contract--and you're saying the costs to do that, to bring in all those people, to participate in the same things that they're getting at Beatrice, costs more than just having all those services right there. Is that the... []

MARGARET HUSS: That's right. That's right. And...right. And the people who now live at BSDC are high-needs people and they are probably more expensive to care for than a mildly retarded person who can navigate in the community on their own. []

SENATOR LATHROP: Okay. []

MARGARET HUSS: That's part of it. But I will add that this article, as this article points out, when there are savings, and again this article is a review of 25 years of other articles, looking to see if things that they found could be generalized. When savings do occur in the community, this article concludes that they only occur when services are cut and quality of care suffers. So there are ways to save money, but it's at the cost of

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compromising care. []

SENATOR LATHROP: Okay. The reason I bring that up and that I wanted to summarize the point of the article is that if anybody wants to address that point that you're making with the article and that you made with your testimony, they should feel free to. Because I think that is a...I don't want to call it fact but it's something that people talk about when they say there's Beatrice, we could save a lot of money if we move these people to a community and use that providing more services. []

MARGARET HUSS: Exactly. I know that that is a commonly held belief, both here and many other places. That's why I thought it was important to bring this article forward because this is a, you know, it looks at all sorts of stuff and comes to some general conclusions that might be useful in policymaking. I do have other copies of that article if there are people in the audience who...I don't have enough for everyone, but I have a few in my things I'd be glad to share. []

SENATOR LATHROP: Okay. And one other point and that is you are the second person already this morning to talk about the appropriateness of Beatrice for the profoundly disabled and referred to those with mild disabilities as able to navigate in the community setting. Your judgment, if you can--you sound like you've studied this topic, not just serving as a guardian for your brother but you've studied the topic so I'll ask you--where's the line at which a person in your judgment is...reaches a level of profound disability or profoundness in their disability where you think that Beatrice is the appropriate setting, versus someone who's more mild and might do better in a community? []

MARGARET HUSS: I don't know. I think some of that is driven...will be driven by the person and their needs. What, you know, what the law says and what is that there are usually three things you look at and it's...community placement is appropriate where the person can benefit from it, where there are resources available, and where the person

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chooses it, or their guardian. And sometimes it's the professionals who say, this person could really benefit from what's going on over here, and that's how you find out about whether it might be appropriate. Most of the people, I believe, at the State Developmental Center have been adjudicated mentally incapacitated so they have guardians so they're not capable of, what I guess it would be, making an informed consent decision. Every time my brother needs some healthcare, he's, you know, we may try to explain something to him but he's not capable of deciding if he's going to have this procedure or that. That's my decision. And I think that that's what makes it difficult. I think if a person has a guardian, then it's a person who needs help making those sorts of decisions and looks to professionals and to their guardians for that. []

SENATOR LATHROP: So you regard it not as a level of profoundness in a continuum or a spectrum, but a decision of the guardian. []

MARGARET HUSS: Well, the guardian is acting on behalf of that person and in their best interest. If the person is able to...I think we've seen...I've seen people who once lived at the State Developmental Center because of a historical anomaly that that was the case back in the day. I guess there used to be 3,000 people there and many of them didn't belong there. That was true across the country. When I see those people, I am amazed and I think it's wonderful that they never belonged there, obviously. And I don't think that the institution is for everyone and I don't think that the community is for everyone, and I don't know where you draw the line because I'm not a professional. []

SENATOR LATHROP: Okay. []

MARGARET HUSS: But I do think that it's best for people with profound disabilities, yeah. []

SENATOR LATHROP: Okay. Thank you. Senator Wallman. []

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SENATOR WALLMAN: Thank you. Thank you, Senator Lathrop. Yes, ma'am, how did you...were you the guardian that placed your brother there, or your parents did that? []

MARGARET HUSS: My parents were still alive and they...it was, of course, as anybody would tell you here who's a parent, is a very difficult decision. And he lived at home until he was really physically a man. He was, I think, 17, and I'm ten years older than him so I was around and I became a guardian with my parents, who are both now dead. But it was their choice and it was...they looked very carefully at what would be the best place for him. []

SENATOR WALLMAN: So they found out through various agencies about Beatrice, huh? []

MARGARET HUSS: Right. They first went through public schools in Omaha and through the ENCOR program, the Eastern Nebraska Office of Retardation, I believe, and he had services for a time in Omaha and, for him, they were minimal and not appropriate. And Beatrice turned out to be the best of all options. []

SENATOR WALLMAN: Okay. Thank you. []

SENATOR LATHROP: Very good. Thank you for coming down today. []

MARGARET HUSS: Thank you. []

NANCY WEBB: (Exhibit 3) Hi. My name is Nancy Webb. I was in Beatrice for...I went to Beatrice when I was 5 years old and got out when I was 27 years old. I didn't really like Beatrice, but I have to...let me tell you what it was like to live in Beatrice. I did not like living there. Even when you didn't do anything, they still put you over the tub, bathtub, and spanked you. We couldn't go anywhere outside without a staff. The food couldn't go anywhere outside...oh, was not good. We got three meals a day, nothing more. I went to

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school in Beatrice. I worked with the babies. We were not paid for any work. My bed was in the dormitory with about 20 other women. One day we had Dave...Beatrice told me I was getting out of Beatrice. I didn't think this was a good idea. I was...this was my home. There was...there I grow up and this was all that I knew. I was afraid. I did not want to leave. Kathy Kosse and Nancy, another Nancy, two nice women from ENCOR, came to pick me up and take me to my new apartment in Omaha. It took awhile for me to feel comfortable there. Often I will..I felt at home. Omaha has been my home ever since. Life was opened up for me. I have my own friends. Part a friend after working for 33 years where I was paid. I volunteer at a doggy day care, Noah's Bark. I go to Tulley's Kennels with...where I help the puppies to socialize with people. I love animals and they love me. I live with a extended family. I love where I live. I have my own room, my own things, my own...my things and my kitty cat. I don't want to ever to go back to Beatrice again. I want to see the people there get out into the community. Beatrice is not a good place for anyone. My mom always said, let my people go. []

SENATOR LATHROP: Thank you. []

NANCY WEBB: You're welcome. []

SENATOR LATHROP: Any questions? Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Nancy, you were placed there when you were five years old? []

NANCY WEBB: Yeah, and I got out when I was 27. []

SENATOR STUTHMAN: And...27. Do you think with the services that we have now in the communities, would a five-year-old ever be put into Beatrice now? []

NANCY WEBB: No. []

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SENATOR STUTHMAN: You don't think they would because of, you know, the technology we have, the people that work with the individuals in the schools and stuff like that. So it's, you know, I feel kind of bad. To me, it's unfortunate that you had to be there at such a young age. []

NANCY WEBB: Yeah. []

SENATOR STUTHMAN: You know, a five-year-old... []

NANCY WEBB: Yes. []

SENATOR STUTHMAN: ...is really young yet, so... []

NANCY WEBB: Yeah, I went there when I was 5 years old and I got out when I was 27.
[]

SENATOR STUTHMAN: Twenty-seven, so...and you're very content where you're at right now. []

NANCY WEBB: Yes. []

SENATOR STUTHMAN: Okay. Thank you. []

NANCY WEBB: You're welcome. []

SENATOR LATHROP: Very good. Thanks for coming down. []

JOE VALENTI: Is it okay if I pull another chair around? []

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SENATOR LATHROP: Sure. []

JOE VALENTI: Otherwise, she's going to correct me from the back row here, so I just...
(Laughter) []

DEE VALENTI: Cute. Real cute. I'm not done with you yet. (Laugh) []

JOE VALENTI: We need Steve's services. Our name is Dee and Joe Valenti from Omaha, Nebraska. Last name is spelled V-a-l-e-n-t-i. I think I've sent all of you a couple summaries of your previous hearings. I'd like to, before I get into a little bit of testimony, Senator Lathrop, you had a question about assessment and how do you make a decision between, you know, be at Beatrice or a community-based and developmental disabilities. I think Dr. Buehler testified in one of your first meetings in June and I thought he did a great job of doing a little bit of an analysis that needs to be done, and also, as you might recall when HHS testified, there is a program called ICAP which does an analysis also that my wife Dee could talk to a lot better than I could. But again, I think those programs are available to do an analysis on whether or not be it the institutional setting of Beatrice, which really is a misnomer and I agree with the people that have testified before us that it's really a community. It's not an...I wouldn't call it an institution at all. I would also point to you, we'll probably come from a little bit different angle. Our son Donny is 20 years old. Is at Beatrice today. He was first there in 1999. We adopted Donny when he was three and he was originally...and he was born in 19... []

DEE VALENTI: Eighty-eight. []

JOE VALENTI: ...98...'88, '88. So...and we adopted when he was three in 1991. He was first placed in Beatrice in 1999 in the ITS program. I would encourage you, as well as I would encourage HHS, to look at the ITS program as far as the subject we're going to talk about, which is our son is oppositional defiant behavior. If you read the articles which I think have been really well written on the Robbie Hawkins story in Omaha,

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Nebraska, which was very, very unfortunate, the system failed Robbie. The difference between Robbie Hawkins and our son Donny would be that I don't believe Robbie was classified as MR. I think he probably had some intellectual level, which was probably be it the good or the bad news, unfortunately, but his diagnosis, the process that Robbie went through over all of those years since he was four is very similar to our son Donny--in and out of different institutions in Omaha, be it Immanuel Hospital, be it St. Joe Hospital, whatever the case might have been in Omaha at the time. The system is really broken. I can't even imagine the task that you have before you. I'm sure when Senator, Speaker of the House Senator Flood appointed this committee, I'm not sure any of you probably had any comprehension of the depth of the issues that are facing the state of Nebraska. And back to funding, I'm not sure where the monies come from, but all I know is the attorneys always have a saying when we deal with them in my business as you either pay now or pay later. And I think we're going to have to pay now or we're going to pay later. I think the cost of prisons are much higher than the cost of being at Beatrice on an individual basis, and I think you've got other testimony to that effect. So again, we are very supportive of Beatrice. We are very fortunate that our son Donny could be there. He's in a group home type of setting today. The community-based programs I think ultimately really could handle Donny, but as was testified earlier, and I won't be too redundant, the...it's really sad that the oversight, the development of community-based programs in the state of Nebraska have not been truly explored. I think again, I think for some of the folks that have testified, I agree from what they've said and I understand community-based programs would not be appropriate probably for them. But for our son Donny, who is probably, with the oppositional defiant behavior and also an MR classification, he's been terminated from three group homes since 1999 and that's why he's back at Beatrice again. But the reason Beatrice works for him, and I would say, quite frankly, the ITS program really worked for Donny, is because of the level of oversight, the level of training that's available in those kinds of programs. What happens when they go into a group home environment--and I also think I wrote you about this and I also wrote Sean about this, is that...is they do...HHS is required, and appropriately so, to do an analysis under the

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ICAP program, which then funds ours for the placement into the community-based programs. And what happens is there's a disconnect, or whatever the case may be, between the funding and then the group home provider because of how they interpret funding for those hours. And then that gets very, very complicated and one which you probably won't want to get into today because I couldn't explain it if I tried. But the bottom line is they do not...they're not able to staff it to a level which, you know, is appropriate for that need and, i.e., in this case would be one-on-one care. They interpret one-on-one care to be different than what we would interpret one-on-one care and what Beatrice basically is able to provide on a one-on-one basis, and that's really the breakdown occurs, in our mind, with a lot of, I think, consumers who could be placed in community-based programs, is how it's funded and how it's administered. But the training is a huge, huge issue with community-based programs, the training and oversight and management of those programs, be it from HHS who tries but they maybe...I don't know if they're understaffed or overstaffed. Again, I think that's a bigger issue than I could address today. I would also say in Donny's case we had a very unfortunate happening before he ever got to Beatrice, is that to get him the services that he required we had to make him a ward of the state. Again, that's a much more complicated topic than you'd want to get into today, but again I think there's a lot of...like I say, there's a lot of dysfunction in the system. And we were paying...and I would go to Senator Stuthman's question. As much as I hate to say this, some of us are able to pay some funding for our children or our relatives or whatever the case may be. We were paying upwards of \$3,000 to \$4,000 for Donny's care. That ended when we had to make him a ward of the state just to get him the services that were necessary. So that is not a good situation. I mean, if you've got someone paying \$3,000 to \$4,000 a month and then you force them into a situation where they don't pay it any longer because you make them a ward of the state to get the services that he needs, I'd say something is wrong with the system. But again, we are very pleased with Beatrice. I know there's a lot of...and Dee is starting to read the 40 pages or so of the DOJ report. But again, I don't...and I think your question about what happened in the nineties would be my question, too, what changed between nineties and 2008. And also, I would also say to

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you that the public school system, which was also brought up in the previous meetings, the hearings, they do a heck of a job and I would say the Lincoln Public School system did a heck of a job with Donny and did a lot better job than the community-based programs did. And there's a reason for that. They get funded by the counties, as I understand it, and they really have better oversight. And then also I would say that we're very pleased with Beatrice, like I was saying earlier, but the ITS program is there. It's working, at least in my mind. It always worked for Donny for these types of issues. So I think you've got a format, an outline, a summary of how to do it. It's just how you extend it into the community, you know, community-based programs for those types of individuals. And I'll let Dee add what she needs to add. []

SENATOR LATHROP: Can we...let me visit with you, if we can. []

JOE VALENTI: Okay. Okay. []

SENATOR LATHROP: Just...it keeps the record more straight if we talk one at a time,... []

JOE VALENTI: Okay, that's good. []

SENATOR LATHROP: ...and so I'm going to take an opportunity just to clarify something. You talked about the ITS program being helpful and useful and beneficial for your son Donny. Tell us what the ITS program is so that we have that. []

JOE VALENTI: I'll let Dee probably address it, if you don't mind, but it's an Intensive Treatment Program that Beatrice has. It's housed in a separate facility, I think it's, what, 202? Well, it's probably not important. But anyway, but the staffing, quite frankly, is different. It's a much higher level of staffing, at least we feel it is, even though I think he's being cared for appropriately today. And then the follow-up, the continued meetings that you have every 30 days with that staff and the administrator of that program is just

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very intense and they bring a nurse, the physical therapist in, they bring the administrator in, they bring the activities director in. Everybody comes together. The teacher comes in on a every 30-day basis so you're constantly monitoring, you know, monitoring what's happening. []

SENATOR LATHROP: And I asked a question before about where, in my own mind, looking for where Beatrice is a compelling placement and where the community is a compelling placement. Is your son...one of the criteria that we heard in June, when we held our hearings, was safety. Is he a safety risk if he's out in the community... []

DEE VALENTI: Yes. []

JOE VALENTI: Yes. []

SENATOR LATHROP: ...to himself or to other people? []

DEE VALENTI: Yes. []

JOE VALENTI: Yeah, he's been cited a couple times for be it inappropriate sexual behavior, as well as he would run, he would... []

DEE VALENTI: Elope. []

JOE VALENTI: ...flight, elope. []

SENATOR LATHROP: Okay. []

DEE VALENTI: And property destruction. []

SENATOR LATHROP: Okay. Before we have Dee testify,... []

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JOE VALENTI: Okay. []

SENATOR LATHROP: ...let's see if anybody has any questions for you, Joe. []

JOE VALENTI: Okay. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Joe, first of all, I appreciate the fact that you brought to the surface, the fact that you are...you've been paying. You know, you had been paying for services for your son, \$3,000 a month or so like that. But in order to receive a service from the state you had to make him a ward of the state. You had to cut the tie between the family and then you were not responsible anymore for those \$3,000. I have always said that, you know, I would hope that, you know, that a family could continue to help support that. But the fact of breaking that tie from, you know, part of your family to the ward of the state is something that I don't like to see happen. But that's the way it is right now. And I would wish that, you know, somewhere down the line that we could change something like that where, you know, you've got the financial resources to help supplement that and receive those services. I think it could be a win-win situation. But the fact, you know, what...how do you feel about making your son being a ward of the state? []

DEE VALENTI: Do you want me to go ahead? []

JOE VALENTI: Yeah, you can go ahead. []

DEE VALENTI: You know, that was not our choice. We did not want to make him a ward of the state. First off, we didn't even want to place him out of our home. But based on professional opinion and his safety and ours and his growth potential, we needed to

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learn to love him from a distance. So we opted to. He started out in the ITS program, as Joe said. From there he was recommended into community-based services, which he, you know, he was terminated from three of them. I don't know what the magic number is, how many you terminate them from before you try to find another option, but three was enough. You know, making him a ward of the state was the most unbelievable thing I could imagine having to had to do. I mean, we had to do that just so he could get what he needed to be a viable human in society. We had to make him a ward of the state. Where does that make sense? []

SENATOR STUTHMAN: That is one of my concerns too. You are looking for a place for him and willing to pay some. []

DEE VALENTI: Well, absolutely, and we, I mean, we were willing to do whatever it took to make him a viable contributor to society. []

SENATOR STUTHMAN: And you were financially able to... []

DEE VALENTI: Correct. []

SENATOR STUTHMAN: ...contribute. []

DEE VALENTI: Correct. []

SENATOR STUTHMAN: But in order for this...to find that place you had to make him a ward of the state and then they took care of the bill. []

DEE VALENTI: Yes, Senator, that is correct. []

JOE VALENTI: I know HHS is here. Hopefully they're not recording our names and our financial ability or whatever. (Laughter) No. []

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SENATOR LATHROP: They're here. (Laughter) []

JOE VALENTI: They're here. []

SENATOR STUTHMAN: But, no, you know, and I'm sure there's other situations that would be in the same situation that you are, that could financially help if they find the right place for the individual. []

JOE VALENTI: I think as someone testified earlier, Senator, I think that there's just...there's just not this...and maybe there's no way to have a door that you go through and then kind of then move to the other possibilities. You know, you go through so many different doors in there as you're trying to do, and I know it's...you're not going to get it done in just these hearings. It's trying to find a more congruent system, I guess I would say, and it's not congruent today. []

SENATOR STUTHMAN: Thank you. Thank you. []

SENATOR LATHROP: Do you have anything else to offer, Dee? []

DEE VALENTI: No. Honestly, I mean again, I think Joe has said it and I'll just echo what others have said before me and that is, you know, again, obviously, through the, you know, the report that was done on Beatrice, there are some things that can be done better. But you know, I truly do believe it's a systematic problem and it's a lot bigger than Beatrice and it's a lot bigger than our son. And, you know, it's really scary what's going to continue happening and what do we do for these individuals who didn't sign up to live this life? []

SENATOR LATHROP: Right. Thank you. Any other questions? Seeing none, thank you, folks, for coming down. []

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JOE VALENTI: Thank you. []

CONSTANCE ZIMMER: (Exhibit 4) Good morning, senators. My name is Constance Zimmer, Z-i-m-m-e-r. I'm the chair of the Nebraska Statewide Independent Living Council. Nebraska SILC is an organization that exists because of a mandate under the Rehabilitation Act as amended in 1992 to advocate for independent living for people with disabilities. Nebraska Statewide Independent Living Council wants all people with disabilities in the most inclusive environment possible. Over the last few years, we have watched Beatrice State Developmental Center fail Centers for Medicaid and Medicare surveys repeatedly, and then fail a Department of Justice inspection while a report was released by Nebraska Advocacy Services outlining the abuse and neglect people with disabilities suffered. Our brothers and sisters in disability deserve better than this. If a person in society performed the kind of abuse and neglect that occurs at Beatrice, they would be punished by the law. But apparently the state of Nebraska allows it to take place in one of its institutions and it's allowed. When we look at all the different parts of the disability system, we see that it is broken badly. Several speakers before me this morning have said that very clearly. The set of parents just before me made that very clear that the system is not congruent at all. There is abuse and neglect at Beatrice, multiple allegations of rape at the regional centers, the official waiting list for developmental disability services, the unofficial waiting list for services in behavioral health, the Thomas Fitzgerald Veterans' Home in Omaha failed its inspection by the Department of Veterans Affairs, and the cuts to Medicaid services that limit supports and services that people need, people with disabilities need to live in the community. It's an extremely monumental problem. It's very complex. It's obvious that it cannot be fixed piece by piece by piece, but the state has to repair the entire disability system holistically, not just the system that serves people with developmental disabilities, although they have a very significant need for that. We need to make disability services in Nebraska an entitlement. This means that if a person is declared disabled they receive the needed supports and services right away. Another suggestion is to create a

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separate division of aged and disability services. This would keep the system open to all. When things are behind closed doors, we don't find out right away what's going on and especially what's going wrong. Nebraska Statewide Independent Living Council knows this committee was charged with only looking at Beatrice State Developmental Center, but we believe if you do not look at the whole system holistically more problems will develop. []

SENATOR LATHROP: Very good. Thank you. Are there questions? Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Constance, you dwelled on abuse and neglect at the Beatrice State Home. Several times you brought that up. Do you feel that there is any abuse and neglect in a community-based setting? []

CONSTANCE ZIMMER: I'm sure there is. []

SENATOR STUTHMAN: So it would probably be similar to that then too. []

CONSTANCE ZIMMER: And we would need...any community setting programs that are set up and utilized, I think we would have to scrutinize them as closely as Beatrice State Developmental Center and the regional centers are scrutinized. []

SENATOR STUTHMAN: Okay. Thank you. []

SENATOR LATHROP: I do have a question, and maybe I'll ask your opinion because you're maybe the third person already this morning that brought up a notion that Bruce Mason shared with us when he testified in June, and that is the idea of having a holistic approach or if someone needs care they can come into the system and get what they need and right now it's fragmented. And can you tell us what that would look like or what you think we need to do that we're not doing in terms of providing care in an easier way

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for folks that have developmental disabilities. []

CONSTANCE ZIMMER: I think if we had a department of disabilities services, and within that department were the psychiatric services and developmental services and services for the aged, you would have fewer instances of families needing to surrender custody of a beloved son in order for that son to get essential services, because it wouldn't be so piecemeal and you're folding together... []

SENATOR LATHROP: How is it piecemeal now? If I...and just take a hypothetical person in need. They're now through the high school. They've graduated so they're done. The school system is done providing them care or services and now they're 30 years old and they need help. You want to take him into the state's system to get him care, him or her care. What needs to...what's happening now versus what you envision would happen where we have a more streamlined or holistic approach? []

CONSTANCE ZIMMER: Well, if I was queen of the world,... []

SENATOR LATHROP: Let's go with that. []

CONSTANCE ZIMMER: ...when a child aged out of the school system and they can be served under the IDEA until they're 21, that several years before they reach that age or they had to transfer out, the school system, which does unilaterally an excellent job of serving these children and serving them in the community, according to their distinctive needs, they would be transitioned out of that school setting into a community setting and there wouldn't be the gap between the excellent services in the school system and excellent services in the community of their choice. []

SENATOR LATHROP: But you talked about it being fragmented. And I understand that the schools...and that is the one thing that we've heard that's been very encouraging is everybody seems to be complimentary of the way these services are provided through

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the school systems. But where is the fragmentation going on right now? If I want to have...if my son or daughter needs to see a speech therapist, is this...where is the lack of... []

CONSTANCE ZIMMER: When they're no longer in school, you're on your...if your child is with you, you're on your own to try to find somebody who will serve your child. Many caregivers, providers, professionals will not serve a child with disabilities. I have a son with severe...multiple and severe disabilities. He only, in his lifetime, have spent one month in an institution. He has lived with us all the rest of that time. He's 24 now and is living independently in the community, but that took...was virtually full-time work by two parents to make that possible. []

SENATOR LATHROP: Let me back up. If you want to get speech services, if you want to then get physical therapy, occupational therapy, and to have a psychiatrist involved in his program or treatment, do you have to go to a different department in state government to make all that happen, or is there one contact? Maybe that's what you're saying--there ought to be one contact and these things just happen. []

CONSTANCE ZIMMER: One department of disability services that would be able to point you towards the resources and help you coordinate them. Now you have to go and find each and every one of them. It's very hard to convince one, the dentist, to talk to the speech therapist, or the occupational therapist to talk to the primary physician. But if there was a coordinated system it would work much better and their quality of life would improve. []

SENATOR LATHROP: And how has that happened? If you take your son to dentist A and to speech therapist B, what's not happening today that you think is going to happen under a different system? I'm just trying to learn. I'm not... []

CONSTANCE ZIMMER: That system would also be providing case managers and

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resource developers, people who would be developing the resources that would serve people, case managers who would be able to interact with the professionals and lead them to collaborate with parents and so the child can live a life in the community. That's very hard to do personally. []

SENATOR LATHROP: Are we missing...okay, are we missing then the case coordinator? []

CONSTANCE ZIMMER: Case coordinators, we are. And another thing we're missing that would be very important is resource developers, people who develop the resources, find them, make them available. And we also are developing a set of peer reviewers who can make frequent visits to community sources of service to make sure that their quality is what it should be. []

SENATOR LATHROP: So your vision, when you talk about having it less fragmented, your vision would be that there would be a coordinator, somebody out there developing providers so that you don't have to call 42 dentists to find someone that will treat someone disabilities,... []

CONSTANCE ZIMMER: Uh-huh. []

SENATOR LATHROP: ...and then someone who's also going to oversee or make sure these are good folks. []

CONSTANCE ZIMMER: Peer reviewers who are making frequent and often...and come often visits. []

SENATOR LATHROP: Okay. You've answered my question. I appreciate that. Are there any others? []

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CONSTANCE ZIMMER: Thank you. And I can't iterate enough how the school systems have figured out how to do this and perhaps we need to consult with some of the experts in the school system to find out how to do it without dropping stitches. []

SENATOR LATHROP: Okay. Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. I guess, ma'am, in regard to the school systems, I appreciate what you brought up. I used to be on the school board. Do you think that the school systems, the community-based, you know, care people should get in contact with the school system and that would be a resource for them? And also what if nobody takes a child in community care? Then what would you do? You know, I appreciate you take care of your son or daughter by yourself and I know that that's a job. And so what would be your options then, you know? What do you feel? The state has to have a... []

CONSTANCE ZIMMER: To have there be significant interaction between that child's IDEA team and wherever they are going. They're going to...that child is going to live somewhere--they're either going to live with their parents; they're going to live, Beatrice; they're going to live in a group home--but to have a lot of interaction before that cutoff date. Because the schools have figured out a program that works very, very well for that child and it's very distinctively individual, you can be sure of it. And I think the school system has a lot to teach us and the other disability systems about how to be inclusive and serve people in a community, because that's where they serve them, in inclusive school communities. []

SENATOR WALLMAN: Thank you. []

SENATOR LATHROP: Very good. []

CONSTANCE ZIMMER: Thank you. []

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SENATOR LATHROP: Thanks for your testimony. []

SANDRA HAM: I do have handouts. Good morning. []

SENATOR LATHROP: Good morning. []

SANDRA HAM: (Exhibit 5) My name is Sandra Ham, H-a-m, and I live here in Lincoln. And I will warn you I do have a written text here but I probably will end up going off, just based on some of the conversation we've had this morning. I want to thank you for the opportunity to speak to you today. I'm here, of course, to talk about BSDC, but I'm also here mainly to talk about community placement options for BSDC residents. My son has lived at BSDC for the past six years. Ian is currently 23 years old and he was diagnosed with autism as a toddler. He also developed insulin-dependent diabetes at age seven. Diabetes is a difficult diagnosis to deal with, but especially so for someone who has a developmental disability. Prior to BSDC, Ian lived in a group home setting. He received services from two different providers over a period of a little over three years. In the group home there were many issues. I can't even begin to go into all of them. There was a constant staff turnover; inadequately trained staff in diabetic care; very little, if any, medical and nutritional supervision. The staff operated pretty much on their own, particularly with the first provider we had. The overriding concern for both providers was profit. Ian was at risk because of the diabetes and development of behaviors of elopement--running away. There were escalating numbers of police calls to aid in the search for him, or calls because of citizen encounters with him as these behaviors developed. These calls also often included paramedics to assist with the medical needs when he was finally found. I will briefly describe only three incidents to convey the seriousness of the risks he incurred. One incident that occurred required a police officer to be called to a convenience store at midnight. The police officer saw a nonverbal teen and thought my 16-year-old, disabled son was high on drugs. They handcuffed him, in the process stepping all over his bare feet. When they saw the MedicAlert bracelet, they

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proceeded to the nearby group home. The knocking on the door woke up the sleeping staff person. He was unaware Ian had even left the house. Another situation involved a group home staff person stopped for DUI. My son was a passenger in the car at that time. This same person had been responsible for blood testing, insulin dosage, injections, and meal preparations for Ian, in addition to being responsible for other daily needs typical of a developmentally disabled child. The third and worse example was when Ian ran away from the group home at 8:30 in the evening with no coat on a bitter, bitter cold, winter night. The police, group home staff, and I searched for him. The local TV station made a plea to the public to watch for him. And finally, two and a half hours later, he was found miles from the home. We are thankful that he survived. And, senators, as we drove and drove, seeing the two police cars that had been part of that search drive past me, the thought that went through my mind was they found my son's body, not my son alive. It was a most horrendous night. After months of trying with other events that I haven't even listed, I finally got the news that Ian could move to BSDC. My son has finally gotten what group homes could not or would not provide. There is always staff to monitor Ian 24/7. There is always a nurse on call 24 hours a day. Most importantly, there is oversight constantly. While I agree improvements are needed, BSDC is a superior provider to any of those in the community-based setting. BSDC is the safest place for my son and others with high medical and/or at-risk behaviors. And I would like to touch on a comment made earlier, a question about abuse in community homes. Oh, most certainly there is, because I personally made reports and I know my son's doctors made reports, and I know a teacher that reported abuse allegations, and the only investigation was done a week after he left that first provider and, by that time, he wasn't there and all of the original staff that these allegations concerned had left, either on their own accord or after being dismissed. So please, please don't think that a group home is this wonderful environment of caring people, not to say that there aren't some, but in many instances there was one person to care for five boys. My son was given high hours, high needs, high dollar hours. He also lived with two other boys in a similar situation. They all collectively probably should have gotten close to one-on-one staffing, and in the mornings there was one person to care for those five children. The

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group home situation, in my opinion, for a high-needs person, is not and will not be the answer. They are not willing to spend the money necessary. Even if they are funded, they will not spend the money necessary. The bottom line is and will always be profit. Thank you. []

SENATOR LATHROP: Thank you. I do have a question for you. You've brought up, maybe for the first time that I've noticed this morning, the idea that someone with high needs can go into a community-based program. They go through an evaluation process that decides how much money is going... []

SANDRA HAM: Uh-huh. []

SENATOR LATHROP: ...to paid for that person. And are you suggesting today with your testimony that the person may be evaluated, the evaluation may show that they need to have one-on-one care, but when they get to the group home they don't necessarily get the care that the evaluation... []

SANDRA HAM: Yes, absolutely that is the case. Absolutely. []

SENATOR LATHROP: That would be your experience. []

SANDRA HAM: Without a doubt, with my son and, like I say, with other children that were in specifically the first group home provider. They had a situation where legally they should have only been allowed to have four boys, but there's some glitch that allows for emergency placement. That emergency placement was a long-term situation that only ended when I and two other parents pulled our children from that home because of all that was going on in the way of abuse and neglect. []

SENATOR LATHROP: I'm sure that there are, you know, there's very good community-based providers and there's some... []

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SANDRA HAM: Certainly. []

SENATOR LATHROP: ...that are trying to do it by the seat of their pants and make money. []

SANDRA HAM: Yes. Absolutely. []

SENATOR LATHROP: And so I don't know about how a generalization like that carries over to all providers, but you've brought the subject up and it's something that we can watch for. []

SANDRA HAM: Definitely. And I do...please, please allow me to say I have come across amazing people that worked with my son in the group home. One in particular loved my son dearly and cried when he had to go to Beatrice, but she understood why that was necessary. With every behavior, with every elopement he was coming closer and closer to injury or death for himself. And I also want to point out that police and firemen were called, other individuals helped in these situations. There were times he was in public places, he went into private homes. At any time he could have, inadvertently, hurt someone just by trying to run, pushing them. Someone could have interpreted him as an intruder, as the policeman did, perhaps on drugs and chosen to defend themselves. It was a constant, constant concern prior to getting him placed that a situation like that would occur, or him running. He would go miles from where he lived, running down 84th Street, running down O Street, the chance that he could dart in front of a car and someone would crash into another vehicle to avoid hitting him. I mean, there was just so much going on. And even the best of those in the group home and the most committed just didn't have the ability to protect him. You know, it really does come down to, even with the best of group homes, they just aren't set up for someone with these at-risk behaviors and this high medical needs. []

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SENATOR LATHROP: Okay. Any other questions? Senator Adams. []

SENATOR ADAMS: Did your son get services from the public schools? []

SANDRA HAM: Oh certainly, excellent services. []

SENATOR ADAMS: Okay, you've already answered part of the question. So you thought those services were good. []

SANDRA HAM: Absolutely. []

SENATOR ADAMS: Where would you say there was a break point between the good service that the school was providing and maybe a limbo that you were put in as to what to do next, and what...it's been brought up before, what could we learn from that? []

SANDRA HAM: I really was uninformed as to what options were out there. Ian lived in my home. I'm a single parent and I was his only caregiver, pretty much unaware that there was even support out there. I had a health crisis and that's what prompted me to place him in the group home. Prior to that time, I did it all myself. The disconnect really is communicating to parents options and, as you've heard from other people, the availability of these options, because sometimes we're talking waiting lists. In my situation, I didn't have to declare him a ward of the state. My situation allowed him to be placed at the top of the list and get services. But I'm a rare person. You know, there's many that are still waiting for that support that would like to keep their child in their home but they need that help. It is a very difficult situation to do with a married couple, yet alone a single person. And while the school tried very hard, they can't necessarily bridge that community involvement, those other things that aren't necessarily explained to them. It was a long process of calling people and getting bits of information and someone else might lead me to somewhere else, but I had to do it on my own. No one shared that. []

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SENATOR ADAMS: So as long as...excuse me. As long as the school was involved, you knew where to go to get...to ask questions. []

SANDRA HAM: As it related to school, I did. []

SENATOR ADAMS: Right. []

SANDRA HAM: I cannot say...there was some information shared, but I wouldn't say there was a packet handed to me with here are some great resources for you and your son, here are agencies and programs that you might be interested. That did not happen. That developed on my own investigating and calling. []

SENATOR ADAMS: Okay. Thank you. []

SANDRA HAM: Anything else? []

SENATOR LATHROP: I don't think so. []

SANDRA HAM: Thank you. []

SENATOR LATHROP: Thank you for your testimony. []

SANDRA HAM: Uh-huh. []

SENATOR LATHROP: I think before we take the next person, we'll take ten minutes just to give the committee members a chance to get up, move around, stretch your legs. Thank you. []

BREAK []

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SENATOR LATHROP: (Recorder malfunction) There were an awful lot of people that raised their hands and I appreciate your limiting your testimony to ten minutes or so, and we're doing well but let's start with the next speaker. Good morning. []

LAURA LIVELY: Morning. My name is Laura Lively. I'm from Omaha. Our daughter is at Beatrice. She's 57 years old and has been there for 40 years. We're very satisfied with her treatment. She was a very premature baby and blinded by too much oxygen in her incubator, and also profoundly retarded because of an immature nervous system. She functions about like a two- or three-year-old, which many of our adult children there do, and has to be supervised and treated like a toddler. It's a perfect place for this kind of child because there's no other facility for that, and it's very frightening to think we might lose it. There have been so many agencies involved in criticizing Beatrice the last several years that we've lost sight of the good things about it, and there really are many good things. The staff that directly cares for the residents are, for the most part, on a par with saints, as far as I'm concerned. The problem now is many of them are retiring because they've been there a long time and we're getting new people, and younger people don't always want to do this kind of work so we have to have some incentive for them, and I know that you understand that. It just seems like so many agencies have become involved that we've lost common sense in thinking about these really low functioning people. It's wonderful when they, you know, can go into the community but this type of child can never handle that. So that's what I have to say. []

SENATOR LATHROP: Okay. Thank you very much. []

LAURA LIVELY: You're welcome. []

SENATOR LATHROP: Let me make sure there are no questions before we excuse you. Senator Stuthman. []

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SENATOR STUTHMAN: Thank you, Senator Lathrop. Ma'am, your daughter receives those services at Beatrice. Are there a number of people that are in that same environment that receive the services? []

LAURA LIVELY: Yes. Yes. Uh-huh. []

SENATOR STUTHMAN: Okay. If your daughter went to a community-based service, do you think there would be that group of people there? Would she be just the only one receiving the service? And do you think there is...or are there services to be provided? []

LAURA LIVELY: For years they've tried to establish that kind of a facility and it hasn't been done. Years ago Dr. Menlosino (phonetic) tried to do it, a unit that he started within county hospital, but it never really got off the ground. And the safety of this kind of resident at Beatrice is imperative. They just...they have no judgment and no ability to, you know, make decisions. It's really sad. []

SENATOR STUTHMAN: So there would be real...it would be a difficult situation if your daughter had to be sent to a community-based service... []

LAURA LIVELY: Very. []

SENATOR STUTHMAN: ...if there was some provided, and there may only be one or two individuals. []

LAURA LIVELY: Yes. I would feel that she was not safe there. []

SENATOR STUTHMAN: Okay. Thank you. []

SENATOR LATHROP: Thank you. Any other questions? Thank you, Ms. Lively. []

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PATRICIA CRAWFORD: Hi. I'm Patricia Kelly Crawford. I live in Omaha. Our son Matt is a resident at BSDC and BSDC is a wonderful home and an essential facility tailored to fit the needs of residents who have severe and profound mental retardation and multiple handicaps. A significant asset is the documentation of incidents which triggered this investigation. The identified incidents are painful for all concerned, but it's impossible to improve any program if there's no record or admission of events which need to be eliminated or modified. The Centers for Medicaid and Medicare, which makes the...has a huge book of rules--it's about this big I think--for ICF/MR. BSDC is an ICF/MR, an intermediate care facility for mental retardation, is enormous and a real protection for people with intense needs. Our family with other families has great respect and appreciation for the dedicated and caring staff of persons who perform very difficult jobs. Matt has been at BSDC since age 14 and is now 47 years old. The middle of five children, he lived at home with his two sisters and two brothers, his dad and me, and attended a day program from the time he was about three years old. His care was always difficult for all of us, but mostly for me. From about age ten or so it became obvious to our family that we were not able to meet his many needs, as his behavior became very difficult to manage. He has no speech, has profound mental retardation and needs a great deal of support in his life. And I'll never forget when we...the first time we ever visited him after he went to Beatrice. As we were preparing to leave, he sat in a chair as far from the door as he could get and I called him and said, Matt, come here, give us a kiss good-bye, and he wouldn't move. And so, you know, he has no speech at all, so I interpreted that as to say that he...this is my home now, leave me here. The two ladies who received him when he entered BSDC still care for him today--now that's got to be kind of a record--along with other dedicated staff members on three shifts. He thrives on the structured schedule which is a source of security and contentment for someone who has no speech and very limited receptive language. His needs dictate three shifts of staff daily for his safety. He benefits from protection from ordinary hazards such as traffic, and he swims every Saturday in a pool with no deep end. He's joyous when his dad and I visit, and is similarly happy to see us leave. For Matt, it's his least restrictive environment. And I thank you for taking on this important investigation--I

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knew when you took it on that you didn't know what you were getting into workwise (laugh)--using your free time to improve BSDC and it's very much appreciated by all of the parents and relatives, and we do hope you'll finish the job for people with mental retardation by investigating community services as well. And we certainly strongly recommend a substantial raise in pay for direct-care staff, which will attract young workers and augment the staff now and in the future, and contiguous states pay workers in ICF/MR considerably more than Nebraska. I'm going to answer some of the questions that were asked earlier. I've been taking notes. The thing about OAITs, that the Valentis mentioned, it means outreach and intensive services system, and they set it up at Beatrice State Developmental Center with the idea that people from Lincoln or wherever could bring their difficult clients and retrain them, and then those people rendering the OAITs service would train the teachers, the parents, the group home people how to deal with a person with difficult behaviors. But so often what happens is they take them off all the drugs and they get them squared away and to behave better and are more happy, but then the community programs don't want them back and so then, you know, they end up staying at BSDC. And I'd like to say this in regard to costs and so forth. At BSDC, this is what people would need in community-based programs, and it's probably an incomplete list: a psychologist, M.D., nurses, including...I don't know what I wrote there, dentist, recreation, transportation, dietician, speech therapist, occupational therapy, social workers, P.E. instructor, and work opportunities. And in that regard, Matt, he is paid for his work. He wears high-end sandals and he owns a couple of pieces of furniture which he's bought with his wages. And I'd also like to make you understand that every month several hundred dollars from his dad's Social Security goes to Matt's support there, and before he was...he went there at 14 and when he became 19, I guess for those five years, we paid big bucks for his treatment. And another thing that's interesting. We've got two dental schools and two medical schools and we've got plenty of nursing schools in this state. I've always thought that their students should be rotating through Beatrice State Developmental Center, which eventually they'd end up in community-based...in communities practicing medicine or whatever, and then they'd have some experience. They will have seen profoundly

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retarded people or severely retarded people before and might accept them more easily into their practice. And then I think this...regarding the Olmstead decree, recognized an ongoing role for publicly and privately operating institutions, and I quote: We emphasize that nothing in the ADA--that would be the Americans with Disabilities Act--or its implementing regulation condones termination of institutional settings for people unable to handle or benefit from community settings, nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. So I thank you very much. []

SENATOR LATHROP: Thanks, Pat. Appreciate your testimony. []

PATRICIA CRAWFORD: Do I just put this here? (Exhibit 6) []

SENATOR LATHROP: Yes, that's perfect. And you filled out a sheet and put it in there as well? []

PATRICIA CRAWFORD: I did do that. []

SENATOR LATHROP: All right. Let's see if anybody has any questions for you before you get away. []

PATRICIA CRAWFORD: Oh, sure. []

SENATOR LATHROP: Senator Adams. []

SENATOR ADAMS: I'll ask you. Have you seen a decline in care in the last...since the 1990s? []

PATRICIA CRAWFORD: At BSDC? You know, I really haven't in my son's living unit, his cottage, but I'll tell you we had one...we had a couple of really good CEOs of BSDC

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probably in the nineties. We had Hugh Sage, who was excellent, and then we had Ken Peterson after Hugh Sage left, and Ken Peterson, God rest his soul, he died at age 50, but that guy, he would...he said, I run a 24-hour facility, he said, so he would visit the various residences during the night, you know, at 2:30 in the morning or something like that and pat the people on the back and thank them for their service, and he'd see the second shift another time. But I'll tell you, the parents really appreciated that loving care he gave, so that would be the downside, is that I think in recent times we've had, oh, since about the mid-nineties, we have had not very effective CEOs. Now I'm not saying about Ron Stegemann, because he's only been there for a very short time, but we had one CEO who was fired and then we had kind of a triumvirate, or something like that, for awhile and that didn't work out very well at all. And now we have the new CEO so we are very hopeful that he'll do a really good job. Okay? []

SENATOR LATHROP: Okay. That's it. []

PATRICIA CRAWFORD: Thanks a lot. []

SENATOR LATHROP: Thanks for coming down, Pat. []

PATTY BRUMM: (Exhibit 7) Hello. My name is Patty Brumm, B-r-u-m-m, and I guess he's giving you a copy of what I'm going to testify. And I want to thank you, the committee, for allowing me to speak today. My sister Jeanne resides at the Beatrice State Developmental Center and has been there for 20 years. She has moderate mental retardation, as well as profound emotional problems. After thoughtful consideration, it is our family's opinion here needs can most suitably be addressed at BSDC. We believe community placement would be detrimental to her welfare. Jeanne's immediate family includes her father Steve, who is here today; her sister Mary, also present, who is a retired teacher; her brother Bob, a practicing M.D.; and myself with a background as a pharmacist. Jeanne is currently 52 years of age. She has recurring, severe emotional problems. Despite being on medication, she continues to have a high

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risk for violence, both self-directed and directed towards others. As a youth, Jeanne was shuffled from school to school, program to program. She was expelled from all of them. These include LARC School and General Arnold School in Lincoln, both public special education programs. She was expelled from private facilities, such as Villa Marie in Waverly and Harry S. Truman Neurological Center in Kansas City. All explanations for the expulsions cited her extreme aggression toward herself and others. Eventually, when all attempts at placement failed, Jeanne was placed in the Nebraska Health and Human Services system at the age of 15. She began her residence at BSDC in 1988. At BSDC, Jeanne's multidisciplinary team of caregivers can be assembled quickly to troubleshoot her problems in crisis situations, such as an escalation in Jeanne's extreme emotional and physical outbursts of self-injurious behavior and aggression. Her team includes specialists in the areas of psychiatry, psychology, social work, physical therapy, nursing, pharmacy, direct-care staff, case managers, and others. Their efforts have been valuable. Most of Jeanne's team are employed on site and are within walking distance of each other. They frequently work with Jeanne and can observe here in her own environment, enabling them to expedite a proper plan of action. An example of the team working effectively is a situation where Jeanne was unable to see her new psychiatrist in the on-campus clinic, so the BSDC pharmacist escorted him to her living unit where he could meet Jeanne and evaluate her. This would not happen if she were in community-based housing. With all due respect to community-based services, in our opinion, this rapid response could not be possible in the community where care is decentralized. We know how difficult it is to get health professionals in the same room, particularly on short notice, because the logistics are too cumbersome. In our view, it is impossible for a team of professionals who likely are dispersed throughout the city to assemble with little notice to address emergency type behaviors of one of our clients like Jeanne. These emergency situations are not emergencies in the sense of a cardiac arrest but, rather, where a patient is in extreme mental distress and would harm herself and others. Jeanne's current ability to see her physician, dentists, physical therapists, pharmacists, and many others within walking distance of her living unit cannot be matched in community-based housing. In the community, a visit to a physician would

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involve getting Jeanne into a car, driving an agitated client, and waiting in a waiting room. Each step of this process has a high potential for failure due to Jeanne's tendencies toward disruptive behavior, which is obviously not compatible with a roomful of waiting patients. Consequently, the doctor's visit would often be postponed. Considering Jeanne's behaviors, we anticipate most of her appointments would be delayed to the detriment of her mental and physical health. Our loved one Jeanne benefits significantly from the controlled environment at BSDC where she has a multidisciplinary team who know her. She needs direct and easy access to all these professionals who communicate directly with each other. We fear the necessary coordination of care and treatment for Jeanne cannot be accomplished by a group of community-based and geographically diverse caregivers who primarily communicate with written notes and reports. We urge the Nebraska Legislature to provide adequate support and ensure proper funding for BSDC and its important mission of meeting the needs of its disabled residents. We believe such a setting must continue for all individuals who will fail in community-based situations. Thank you. []

SENATOR LATHROP: Thank you, Patty. Are there any questions? Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Thank you for your testimony, Patty. []

PATTY BRUMM: You're welcome. []

SENATOR STUTHMAN: The success of your sister you feel is mainly because of the team of workers at BSDC that has... []

PATTY BRUMM: Yes, that contributes largely to it, uh-huh. []

SENATOR STUTHMAN: ...has made the difference, as compared to the

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community-based setting where there probably isn't that team there to work with? []

PATTY BRUMM: Yes. And I know in the community-based setting you wouldn't have a physician right on campus where you can actually walk to the clinic. There's neurology clinics, ENT clinics, ortho clinics, you know, all these different clinics, they're readily available. And Jeanne, with her behaviors, be very hard to get her into a doctor's office if you could find a doctor who would see her, as I'm hearing maybe that's not even possible out in the community. []

SENATOR STUTHMAN: So you're very content with the fact that that group of people, she's able to visit with them, address the situation, and that's been the success at BSDC. []

PATTY BRUMM: Yes. And they include us in on phone conferences while they're meeting if we cannot attend. They have special meetings with her because she has these emergency-type situations, and we've been on phone conferences so we can be included as a family. Of course, we're welcome to come out and be present, but I'm from Omaha and can't make it short notice and her dad is from Lincoln. And so often we are included and I just feel that I like the multidisciplinary approach which I just don't see happening if she's not at a place like Beatrice. []

SENATOR STUTHMAN: Thank you. []

PATTY BRUMM: You're welcome. []

SENATOR LATHROP: I do have a couple questions for you. Your sister Jeanne, is she a safety risk if she's out in the community? []

PATTY BRUMM: Yes, she is. She's a risk to herself, because she has self-injurious behavior, and she probably would exhibit some of those behaviors of trying to run away.

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She can injure others as well. So I think she would be a risk. []

SENATOR LATHROP: Did she ever have a go-through any community programs, or did she go right to Beatrice? []

PATTY BRUMM: No. []

SENATOR LATHROP: You talked about some of the things that she did before she was 15, but... []

PATTY BRUMM: No, she...at the age of 15 she entered the regional care system and she was not a ward of the state. My mom and dad were her guardians and they did pay for that until she was of an adult age. []

SENATOR LATHROP: All right. []

PATTY BRUMM: No, there weren't any community programs that would have taken her at that time. []

SENATOR LATHROP: Okay. Very good. Thank you. []

PATTY BRUMM: Okay. Thank you. []

MARY ANGUS: (Exhibit 8) Senator Lathrop, members of the committee, my name is Mary Angus, M-a-r-y A-n-g-u-s. I am the registered lobbyist for the Arc of Nebraska. As I sat here, I've got a prepared presentation, but I wanted to let you know that I would like to answer some of the statements that were made. Some of that will be in my testimony. The Arc of Nebraska is a support and advocacy organization with and for people with developmental disabilities. We are an affiliated state agency of the Arc of the United States and have 17 local chapters and approximately 2,500 members across Nebraska.

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We live by the core values of mission and principles, leadership, community participation, diversity, integrity, and excellence. We advocate for the rights and full participation of both children and adults with intellectual and developmental disabilities. We recognize the importance of this committee and, as others have said, you've got your work cut out for you and really admire you for your willingness to work on that. You've asked us to assess the Beatrice State Developmental Center. I'm not going to go into everything that you've already seen in terms of the evidence that has been presented to you through the CMS, or Centers for Medicare and Medicaid Services, reports; Nebraska Advocacy Services; and the Department of Justice. You have all seen those reports. What I'm going to do is kind of focus on fleshing out a few things. Obviously, they've already established that they have failed to be in compliance and have been seen as in violation of the Civil Rights for Institutionalized Persons. They have a longstanding, longstanding problem with staffing. In addition to understaffing, which has been shown in all the reports as being over the years, they have many staff who float from one unit to another. These staff often have no knowledge about the unit, nor do they have knowledge about the people who are on that unit. Many have no basic care training. They are assigned to people who may have G-tubes, feeding tubes, or J-tubes, which is especially a problem because if they do not know how to manage the pumps, when to change the feeding bag or when to...how to position someone who is using a tube, we can have many problems such as increases in the risk of pneumonia, complications with medical devices, and delays in getting medical treatment. The communication is a problem. There may be not enough communication between managers and direct-care staff. People who work there have expressed greater levels of stress and fears of suspension. They don't have any understanding as to what that might mean, how they might be suspended and when that might happen. You might want to ask employees tomorrow about what's called the "West Texas vacation." That is something that they use as a reference to being on suspension and there's kind of like a...it's a trophy kind of thing if you manage to make it through and survive a suspension. We've heard about families that have been apparently very, very fortunate in their care at Beatrice. As we heard in testimony on the 23rd, Beatrice has too few professional

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staff. In the June hearings, we were told there are 30 percent of the level of people needed for the numbers there of psychologists. There was at that time, and I don't know if this has changed, no full-time psychiatrist. They should have four to six speech therapists. At that time they had none. They're underserved for neurology and behavior analysis. They have failed to meet goal A-2 of the three-year state plan developed in June of 2007. Two of the objectives which they have failed to meet were an increase in quality assurance at Beatrice and maintain federal certification. I fail to see how they can maintain it when they have not accomplished it. The other thing is to ensure a well-trained cadre of staff at all levels. The reports detail information about staff not having the ability to treat or to work with people with various medical needs, in particular. Beatrice eats up 18 percent of the funding allocated for the developmental disabilities services, but only 4 percent of the people in the state who are using or are waiting for services are in Beatrice. Almost 80 percent of the people with intellectual disabilities who have uncontrolled seizures live in Beatrice...I mean, live in the community. Over 90 percent of those who also are blind live in the community. The percentages that were given in the June hearings were misleading and I believe they presented a picture of Beatrice that would lead you to believe that the population at BSDC has greater levels of disability than those living in the community. In your testimony there is a charge just of the one level, and that would be a level of intellectual disability, showing the percentage of the total population who are living in Beatrice and the total population who are living in the community, along with the numbers that that means. Beatrice is an outmoded, outdated institution which is contraindicated by all of the research and violates the rights of people with disabilities. People with challenging behaviors consistently improve or at least remain the same after moving into the communities. People with complex medical needs sometimes need specialized medical care and services, often are treated, in using creative methods of dealing with those, are treated in the community. The Council on Quality and Leadership reports that we don't trade off on health and wellness or safety when we move people into the community and allow for a greater level of self-determination and choice. People who have grown old in institutions have also been found to be able to move out of the only

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home they've ever known and be happy with that move. Fears that people with intellectual disabilities will be worse off, unsafe, or lonely should not be used as reasons to keep the institution open. Rather than using these scare tactics as excuses, we should identify the circumstances that in the community increase the risk and manage those using such means as personal relationships, social networks, increased self-determination, and increased control. We must develop a holistic and unified service system and supports in the community for people with intellectual disabilities which provide for adequate needs for the ones that have been found to be...found in the assessments. Finally, we have a concern about tomorrow's hearing being at BSDC. The location is very convenient for current employees, but it's problematic for self and other advocates. Transportation is virtually nonexistent, and for people who have either lived there or previously worked there, it can actually be traumatic to return to the grounds. We have provided testimony in your packets from a woman who so fears that she will have retaliation or will be sent back to Beatrice that she wishes to remain anonymous. She was almost afraid to put in any testimony. I have used only her words. The location also reduces the opportunity and the likelihood that the public, in particular people with developmental and intellectual disabilities, will be able to observe the hearing, and the location predisposes testimony that will be favorable to the institution and could serve as a deterrent to individuals wishing to testify about conditions that have been adverse. We believe that it has been...remained open for political reasons--it is best for the town, it is best for the employment situation--but not because it is best for the people who live there. We hope that your charge will be taken without the predetermination that you would keep Beatrice open. In terms of some of the other information that you've been presented, I have on my right here the staffing requirements under the regulations for centers for developmental disabilities is one in eight, one staff to eight persons. In the evenings or off times it is one to ten persons. I can show you the regulations on that if you'd like to see them. The problem with many of the staff there is that they're not trained and that they're overwhelmed by the amount of work that is there. In Department of Justice reports, as well as reports that I've gotten from employees, there is oftentimes a group of people who are not doing any of the work. They are socializing. The

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Department of Justice says that while they were there they were playing cards. That leaves the people who are willing and committed to doing that work to have to frantically get around to get it done. When we have staff that are unable and untrained, unable to be able to recognize a medical emergency when they see it, we have delays in services. In fact, there are times when someone who is using a feeding tube may be aspirating, could be...could be actually turning blue, and they have to call a nurse who may not be very close by. The nighttime, there may be only one manager for the entire campus. The supervision is lacking. There have been times where a nurse has been called, and had she not been called at that point there would have been more serious repercussions. The incident that was reported in the newspaper and to which you've got...you finally were able to get information actually was a case in which the person called for help but didn't realize it was an emergency. And when that person said, we've got a person here who is unresponsive, the operator thought they meant that they were nonverbal or they were not coming when they were called; did not recognize that it was an emergency. So that delayed the system's response even further. I am also presenting you with some testimony from three other individuals who asked me to present it, one of whom is the woman I spoke of earlier who wishes to remain anonymous, another is a parent of a person with Down's Syndrome, and the third is another person who has been in Beatrice...or, no, her mother was in Beatrice and she writes, I would not be here if my mother remained there. She also writes that my mother did not know how to parent me; I was fortunate that my father was able to do that. Because at Beatrice she was not taught how to be a parent. I'll leave these for you, Senator. That's what I have. I think that...oh, I know, there was one other thing that I wanted to say, and that is the folks that have been testifying before me are absolutely correct. We need to have better supervision or better oversight on community providers. One of the problems is that the regulations are different. One of the things that we're going to find, I think, in the LR156 discussions about the wait list is that, you know, we will be looking at that. Another question I heard earlier is other states, do they have wait lists. I have a PowerPoint that was provided in January of this year to the officials in Florida, by officials in Florida. They report that there is a waiting list of approximately

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15,000 people, however, 10,000 of those are children. That leaves approximately 5,000 on their waiting list. I don't know the exact population of Florida, but I would venture to guess that it is the ratio of people...the population to the number of people that are on a waiting list is probably pretty equivalent or we may have actually a higher ratio. I'm not sure about that. I'd be glad to answer any questions that anyone might have. []

SENATOR LATHROP: Yes, Senator Wallman. []

SENATOR WALLMAN: Yeah, thank you, Senator Lathrop. Yes, Mary, I see you're a lobbyist for Arc, which is fine. []

MARY ANGUS: Uh-huh. Thank you. (Laugh) []

SENATOR WALLMAN: But do you have a guideline where you actually train people to be caregivers for profoundly disabled people, nonverbal? []

MARY ANGUS: The Arc of Nebraska does not, but what we have looked at is the figures that were given us in June to show that about 60 percent of the people with profound intellectual disabilities are living in the community. The Arc of Nebraska does not provide any of that kind of training. Thanks for your question, though. []

SENATOR WALLMAN: Thank you. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Mary, in some of the testimony that you have given us, you stated in there that Beatrice eats up 18 percent of the funding, but houses only 4 percent of the people receiving or waiting for services. []

MARY ANGUS: Yes, sir. []

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SENATOR STUTHMAN: What...explain that waiting for services. How do you fund people that are waiting for services? []

MARY ANGUS: Well, no, I was...what I'm talking about there is that when you add the number of people who live in Beatrice, the number of people who are in community-based services and receiving services, and that 1,772 people that we heard about are on the waiting list, those are the people who need services or are getting services. If you divide the number of people who live in Beatrice by the number of people who are receiving or waiting for services, you get the figure of 4 percent. If you do not include the people who are on the waiting list, so you reduce that amount to the somewhat over 4,000 people who are receiving services in the community plus the 276 who are in the institution, then you get a figure of 6 percent of the people in the state who are getting services through the department live in Beatrice. So 18 percent of the funding goes to Beatrice, but only 4 to 6 percent of the people are served there, depending on whether you add the waiting list in. []

SENATOR STUTHMAN: Well, I don't know why you would add the waiting list into it because they're not receiving services or anything, are they? []

MARY ANGUS: No, and that's part of the problem. They have been found eligible but are not receiving services. But I'd be glad to leave it at the 6 percent... []

SENATOR STUTHMAN: Yeah. []

MARY ANGUS: ...and say that 18 percent of the funding goes to Beatrice but only 6 percent of the population of people receiving services live there. []

SENATOR STUTHMAN: Services. []

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SENATOR STUTHMAN: But those are the ones that are needing the highest level of care, right, so...? []

MARY ANGUS: I would disagree with that. We have 60 percent of the people with profound intellectual disabilities who are living in the community. We have almost 80 percent of the people who have uncontrolled seizures living in the community. We have almost 90 percent or over 90 percent of the people who are also blind living in the communities. A case in point is a dear friend of mine who...Tim Kolb, who is ventilator-dependent, quadraplegic, has basically only the use of his facial muscles. He uses a puff and sip tube to control his wheelchair. He lives in his own home with his wife using a care attendant. []

SENATOR STUTHMAN: Okay. The other question that I have is we've heard testimony this morning from individuals that are just very satisfied, you know, with the services that they are receiving there and now you're saying that the reason it has remained open is because it's best for the community but not best for the residents, so...now we've heard of people that are,... []

MARY ANGUS: Uh-huh. []

SENATOR STUTHMAN: ...you know, happy with the services that they are receiving there. They've been through group homes, they've been through things, and now they have finally found a place where the family is content, they're content, and they want to stay there. And in your statement it says, you know, that it's not best for the residents. So explain that a little bit to me. []

MARY ANGUS: Well, respectfully, Senator, I would say that what we have heard from is families and guardians who say they're happy and content with the services. The other thing that I have heard over and over and over again is that there are not adequate services in the community. People have actually, you heard before, had to place their

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child as a ward of state in order to get services. That's not the only area in which you can only get services if you're a ward of the state. That's actually true also in some of the behavioral health services. We have not heard from people currently living there about that. We have heard from a woman who spent 22 years living there who is very, very happy being out. I really couldn't say to you how many people who are actually living there might be able to testify about their contentedness or not. I would just respectfully remind you that they're guardians rather than people who live there. []

SENATOR STUTHMAN: Okay. Thank you. []

MARY ANGUS: Thank you very much. []

SENATOR LATHROP: I do have. In some respects, I'm a little troubled by your testimony and in this...in this respect, I guess, because when this commission was established and the problems at Beatrice became evident and people started to approach me, different groups, folks from your organization and from the Friends and Family of the Beatrice Development Center, it became evident to me that there are two camps and they're philosophical camps. And we have a camp of people that is typified by the folks from the Family and Friends of Beatrice. []

MARY ANGUS: Uh-huh. []

SENATOR LATHROP: They come, as they have today, and testify that things are great and they're very happy and they know that their son or daughter or their ward is safe and secure and getting services. Then we have folks from... []

MARY ANGUS: You can call it my camp. (Laugh) []

SENATOR LATHROP: ...the Arc. Yeah. Well, I'll call it your camp... []

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MARY ANGUS: Okay. That's fine. []

SENATOR LATHROP: ...or the camp that you've just...and I listened to you today and you're...we're very familiar with the criticisms of Beatrice. Believe me, we know that there are shortcomings at Beatrice. But we're hearing people say that's...you know, for somebody who's profoundly developmentally disabled, it's a good spot for them. They're safe. They have behaviors that are...that will get them in trouble in the community, that will make them misunderstood in the community. We need that. And you come in today and you give us the list of the problems at Beatrice and I'm wondering, the philosophy of the Arc is close Beatrice and spend the money on community-based care. []

MARY ANGUS: Yes, sir, systematic closure, yes. []

SENATOR LATHROP: That's, in a nutshell, you have no use for Beatrice or an institution setting and it's your philosophy that everybody ought to be cared for in the community. []

MARY ANGUS: Yes, sir. We've also testified at previous hearings, as a matter of fact when they were discussing setting up this committee, and we have been in communication with families who were unwilling to testify on their own, saying that they were unhappy with the conditions there because they were afraid. []

SENATOR LATHROP: Believe me, there have to be families, certainly people whose son or daughter has sat with broken extremities for four days before somebody figured it out,... []

MARY ANGUS: Uh-huh. []

SENATOR LATHROP: ...or who died because they didn't get CPR in a timely manner. Those things are going on. I appreciate that. But I don't understand why you don't have

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any place for an institution when we have heard this testimony in June:... []

MARY ANGUS: Uh-huh. Yes. []

SENATOR LATHROP: ...There are some people who are at such a safety risk that we can't find a spot in the community for them. []

MARY ANGUS: Yes, I understand that. Yeah. []

SENATOR LATHROP: They can be people who are so profoundly retarded, people whose behaviors make them a safety risk either to themselves or to the folks that they might encounter in the community, and it seems to me that we...that it's not black and white, that there might be, as we try to find what the continuum of care ought to be for people who have developmental disabilities, that there's room for both. []

MARY ANGUS: I understand that. []

SENATOR LATHROP: And I wonder if you'd still be critical of Beatrice if it were well-run and we didn't have these problems today? []

MARY ANGUS: Actually, so much of the research is showing that people benefit by leaving institutions or living in the community. I believe that the diversity of our people in the community can only be enhanced by being experiencing people with developmental disabilities going to our movies, going to the grocery store, living in our streets, living in our block. I will say that there are problems with behaviors. One of the things that we have found is that they either don't deteriorate but more likely are improving. One of the things that we have found is that people who are unable to communicate in the typical sense, I believe it's...well, I'm not positive but I know it's over 40 percent of the people in Beatrice at nonverbal. When you are nonverbal, it's very difficult to get somebody's attention or to be understood in the way that you want to be understood. All of us have

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experienced the frustration of somebody not knowing what we were talking about, not being able to understand, or not wanting to do what we wanted to have happen. As that happens, naturally--and I'm a psychologist by training, a master's level, not doctorate--what we find it that the frustration increases. One of the components of frustration is anger and we become angry and are more likely to act out. As you heard from Ms. Hoell, her own behaviors--and I'll tell you there are people that wish she weren't behaving the way she is now--however, her own behaviors deteriorated when she was in that nursing home. Her own behaviors improved when she left that institution. So I just think that we have to look at...outside of the box. There are things that need to be done in order to increase and improve the quality of services in the community and the wide variety of services that can make a difference. []

SENATOR LATHROP: Okay. []

MARY ANGUS: (Laugh) I apprec... []

SENATOR LATHROP: Well, I just...it seems to me... []

MARY ANGUS: No, I really do appreciate... []

SENATOR LATHROP: ...we're trying...we're here trying to find a solution or at least get our hands around the problem, and... []

MARY ANGUS: We seem unyielding. []

SENATOR LATHROP: Yeah, a little. []

MARY ANGUS: Okay. []

SENATOR LATHROP: I mean not...I don't mean that to be critical, but you obviously

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have a philosophical position... []

MARY ANGUS: Correct. []

SENATOR LATHROP: ...and I guess I don't know that we're impressed that there's no place for Beatrice and the services that it can provide to the people who can't... []

MARY ANGUS: Understand that. []

SENATOR LATHROP: ...safely be in the community. []

MARY ANGUS: I guess one of the things... []

SENATOR LATHROP: That just seems to me to be as black and white as your philosophy. []

MARY ANGUS: One of the things I'm asking is that this committee not have a predetermined notion that it can't be closed. I doubt very much that you would take me very seriously if I said it should be closed today. I would like a systematic closure. I heard earlier that people on my side of the fence, if you will--I'd rather not think of myself as on one side of the fence versus another because I'm here on behalf of people with developmental disabilities with whom we have worked and spoken--there was a comment that people are excited when they hear about the bad things at Beatrice and I will tell you that I, for one, get very excited, but it is not in glee to see that there's more evidence that we should close it. It is in a desperate feeling--how can these things go on? How can we treat people in ways that allow excessive falls, increase risks of pneumonia, etcetera? How can we do that? So my excitement is not in glee. []

SENATOR LATHROP: Right. I believe you. I believe you and I don't want you to think that I look...I take a dim view of your philosophy. I recognize it but, at the same time,

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when we toured Beatrice and some of the testimony we heard in June was... []

MARY ANGUS: Uh-huh. []

SENATOR LATHROP: ...I think they were referred to as blue chippers, you know, the community-based programs. They might come to Beatrice and say, well, here's a person that would be relatively easy to care for, we'll take him into our program. But here's a guy, who maybe he's a runner, maybe he acts out, maybe he will be misunderstood when he approaches... []

MARY ANGUS: Uh-huh. []

SENATOR LATHROP: ...people on the street, and they say, no, we don't have a place for him. And so I don't know. I think... []

MARY ANGUS: What has happened... []

SENATOR LATHROP: ...you make it black and white and I guess I'm not persuaded, at least... []

MARY ANGUS: Oh, I understand that, sir. []

SENATOR LATHROP: ...two months into it, that that's that black and white. []

MARY ANGUS: I also...there have been programs, for instance the crisis intervention team training for law enforcement, that helps them to understand and deal more effectively with people who are in crisis with mental health issues. I think there are a variety of ways that are a little outside the box that we could look at and I guess I'm not going to apologize for having a black and white view. []

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SENATOR LATHROP: You shouldn't, and I'm not... []

MARY ANGUS: No, I understand that you don't. Yes. []

SENATOR LATHROP: ...believe me, I'm not being critical, maybe making an observation. []

MARY ANGUS: No, Senator, you're not being critical. Thank you. []

SENATOR LATHROP: Okay. Senator Wallman. []

SENATOR WALLMAN: Thank you. Yes, Mary, I find it ironic we have a waiting list and why do we have a waiting list? Do we not have enough direct-care providers, you know, at home-based care? []

MARY ANGUS: That's not really the case. What we have is a waiting list because people who have been seen as eligible for services are not getting them because the state has not got that as a priority. Right now, as you heard from Mr. Wyvill, the state does not see community-based services as an entitlement. He actually challenged you to see if you wanted to get a legal opinion about whether that should be the case. The fact of the matter is when someone is deemed eligible or found to be eligible--I guess "deemed" isn't quite the right word--if the service provision by the state is not adequate or they haven't got the money then you don't get the services. That's it. There are also factors that are happening right now that will make it more difficult and more likely that we would need to have a decision that community-based services are actually an entitlement. Because, as you're seeing with the Medicaid reform, one of the things that we've heard today is they're getting speech therapy or they're getting some kind of physical therapy. We just had a cap placed on those treatments in the community. So what we need is to have both the entitlement language and the oversight of community services. There are lots of things that could be done to improve that situation. []

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SENATOR WALLMAN: Thanks. []

SENATOR LATHROP: Sure, go ahead, Senator Adams. []

SENATOR ADAMS: I don't mean to belabor Senator Lathrop's point,... []

MARY ANGUS: Uh-huh. []

SENATOR ADAMS: ...but it keeps coming back to me. So if there are inadequacies at Beatrice and there are inadequacies in funding and, therefore, in services even in community-based programs, why wouldn't we want to direct our attention at providing the quality and, at the same time, why wouldn't Arc favor choices and Beatrice potentially being one of those choices? []

MARY ANGUS: You know, I'm not sure how I would respond to that. I mean... []

SENATOR ADAMS: Okay. []

MARY ANGUS: ...I understand the concept of having that choice of an institutional setting. You know, at the risk of being...seeming more extremist, the situation at Beatrice has been bad for a long time. It was incredibly bad in the sixties and there was actually a lawsuit against the state in order to improve that. The Legislature at that time passed a record number of legislative bills to address community-based services and we were honestly the international model for the provision of community-based services. We can do that in this state. What happened after that is was that services declined in Beatrice again. We found that in the nineties we were starting to have...as you've heard, it seemed to be less quality after the nineties, again, and I don't have enough information to be able to say that, although I do some folks that could probably talk to you about that. []

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SENATOR ADAMS: Thank you. []

MARY ANGUS: Thank you. []

SENATOR LATHROP: Guess that's it. Thank you for your testimony. []

MARY ANGUS: And thank you for your openness with me. Thank you. []

PATRICIA MCGILL SMITH: (Exhibit 9) I didn't know when I would be compelled to come to the fore, but I was just compelled. My name is Patricia McGill Smith, that's M-c-G-i-l-l, no hyphen, S-m-i-t-h. I am a parent and a grand parent of two people with developmental disabilities. My daughter is 38 years old with autism; my grandson is 19 and has Down's Syndrome. And for 34 years I have worked in the field as a professional, working on behalf of parents and families in Nebraska and nationally. I worked 17 years in Washington, D.C., and served in two presidential administrations, administrating special education and rehabilitative services. I only tell you that because my amount of information that I carry is considerably more than the average because of the experiences I have had. I directed the programs, many of which we're talking about right now today. You asked us to assess BSDC and I'm going to skip that because we already have done that. You're aware. You've had all of the reports and the reports are not good. But I sit here today...and I have made so many notes I don't know where to start with my notes, but I know where I'm going to start. I'm going to start with my daughter Jane. My daughter Jane is now 38 years old, but she was diagnosed at age 14 months, and I will tell you the difficulty that I was having and my family was having at that time. If a really fine Catholic priest and a really good physician told me that she should have been institutionalized at that time, I would have jumped at the choice, and they could have made a compelling argument. I have six other children and it is very difficult to raise seven children with a child with special needs, a husband who is having extraordinary difficulties and, I mean, we were just in trouble all over the place. I did not

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make that choice, but I have enormous empathy for the people you have listened to and you will continue to listen to today because of a choice they made that now is causing them so much stress and so much trouble. And I have worked with parents all over the country and, indeed, in many places in the world that have faced some of these same choices. The parents that spoke about the...giving their child up as a ward of the state, when we lived in Virginia, Jane was having these enormous problems and we had legal problems and we had law problems, and I was a single parent, and the state of Virginia offered to have her be a ward of the state. And I said, well, what does that...what would that mean? Well, then we make all the decisions for her. I said, that will be over my dead body. No. But then a very good friend of mine said, but, Patty, what are you going to do if you can't get the help you need? Fortunately, people came to my aid and fortunately we worked through some of those problems, but it is not easy so don't get the impression that it's easy if a parent has a kid in the community. Jane is now 38 years old. I could not believe, if you'd meet her today, the woman that you would know if you knew that baby. I just can't tell you what the community supports that have been around here all these years to help her to develop to her fullest potential have been just extraordinary. Some of the people in this room are some of the extraordinary people who have helped me and my daughter and now my grandson. And I tell you this because some of the information that's being shared would lead you to believe something maybe differently. It isn't that it wasn't easy. When we came back from D.C., we moved back in 2000, we thought we could get community services right away. And there had been a big mix-up on the money, that HHS misplaced a bunch of money, and so there was no admissions. So for a year we had no services. Can you imagine an autistic woman with compulsive...extraordinary compulsive problems with no services? And I think Bob Brinker is in the room and it's because of him that she had gotten some services when we didn't expect it. I mean, have you ever heard of anybody getting services that they didn't have the hours for? My daughter did because somebody had the compassion to understand that that was needed. And why do I talk about Jane? Because I want you to know that the parents who made decisions to institutionalize their children did it for whatever emotional, social, whatever reason if they couldn't take care

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of their person, and so many times I couldn't take care of Jane. And when they placed them they were not wrong. There is a...this two camp thing, Steve. There is a misperception that if you put a person in an institution that you were wrong and we're right, and that is not correct. People make decisions based on their lives and what is happening to them. I am just grateful I didn't make that decision because then what happens is if they...if the institution closed in the next couple years or whenever, what happens, then that decision has to be overturned and that decision is very, very difficult because it was made with so much emotion. You cannot tell me that these people did not have huge emotional stress over making that decision. And so then, when somebody comes along, some young whippersnapper that says, you know, like we're going to fix things up, well, no, it's not such a big fix-up. And I want this committee to understand what the emotions that the parents are telling you today, that these are real and the defense that they have Beatrice is because they found...it was like an island. It was like a place of hope for them. And even when...in the face of reports that say things are not going well down there, the parents do not see it that way. And I don't know if their person is having trouble or not. I can't tell. The reports are pretty dim. You must say they're pretty dim. They're bad. I wouldn't want my child living someplace with reports like that. So it's a real push-pull thing. I mean, it's a tremendously push-pull thing. And I want the parents to understand that when they made a decision they were not wrong, and that's an enormous thing to keep in mind. Because people, like I've said before, they think it's wrong. And I want to talk about the Arc of Nebraska and the Arc of the United States. They moved to the living with the core values of what Mary Angus just spoke, and it took them years to get to those core values. And the reason is, it's actually like why we're sitting in this room today, and they finally determined that they could no longer hedge it, they could no longer say, uh, it's over here, (inaudible). No. They had to declare we will stand by our core values and the core values speak of living in the community. But I wish that your committee could go to some of the places in the country and visit. Go to Minnesota. They haven't had any state institutions for I don't know how many years, maybe ten. How have they done that? You need to ask the questions. There's a wonderful man named Conroy in Pennsylvania that has done the

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research. He has followed like when the institutions closed in Kansas. That's the one I'm most familiar with. They did a follow-up of all the parents and people for like two years, find out are the people happy, are they satisfied, did it go well. I've told you about "No-No Nanette," Nanette Whitesell (phonetic) from Indiana. She is a parent that opposed having her daughter in the community and then, when the switch came, she's going around the country trying to tell people...and I've asked John Wyvill if we could please bring her to Nebraska so she could explain to the parents what she went through and how that all happened for her. I want to answer just a couple other questions that just went by, besides the business of the core values of the Arc, which are enormously important. I'm speaking today, incidentally, as a parent. I didn't...I'm not speaking as the past-president of the Arc. I wanted Mary to do that and she did a fine job. And I wanted for me to be able to just talk to you about the things that I felt were so important. ICAP was mentioned a little while ago. You want to know what some of the problems in this state are? They have underfunded the community-based programs. Why do you think that a service provider would say we can't take that person? We called it cherry-picking in the old days, you know, but they take people that are...don't laugh...they take people who are less disabled because they're easier to serve, quote, unquote. There was a day, and you've got Bob Brinker in this room, and ENCOR has not turned down anybody for like...they're probably at 38 years right now because 1968 was out of the darkness, 1970 began ENCOR, and they have never turned down anybody. They have a medical unit. They have always had a medical unit for children. They have a medical unit that is for adults. I asked Bob at the break. Currently, there are six people living there. They have to live in a medical unit where there's nurses available, where there are people who could work with the G-tubes and whatever kind of tubes or whatever kind of feeding. It is a misperception to not understand that the services that have been talked about. And I, even on one of my pieces of paper, because I was getting so frustrated sitting there, I just made a quick note. Jane has a fabulous psychiatrist or counselor, a service coordinator, the best dentist and doctor in all of Omaha. She has in-home supports; work supports, though not enough hours--I've sued...tried to sue the state twice over it; participates in Curves; works at a program called Ultimate Live, run

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by the Omaha Arc. Respite, lifetime respite care comes every month. I can have like \$125 to help with that. We have...she is in continuing education program to improve reading. She's in a social club, People First. She goes to Sacred Heart Church. She has been an extraordinary minister of the Eucharist only for people at home, you know, at home sick. And she works at the church office and she also works at the Heart Ministry Center. And this young woman, who could not do anything but roll around and not do anything when she was a baby, rides the bus to work on her own. Now how did this happen? And she would be level...in the level, in the beginning, of, let's see, in the beginning she was severely disabled, then she became moderately disabled, and now they think she might be mild except her behaviors with...her behaviors of working with the obsessive compulsive behaviors. She's probably severe and, as an adult, that's a very severe problem. You need to know that the telephones for my house are over there in that bag because I cannot allow there to be telephones in the house with her under supervision. And the good news is, is that with all the difficult behaviors, the police called in, the courts called in and all the things that we've happened, too, because Jane is supported in the community, we have been able to learn how to deal with those behaviors. And there are people in this room that are acutely aware of her obsessive behaviors. Because she can get lost, she can get running...she doesn't get lost but she can go out in the neighborhood and cause trouble. There's a lot of things. She lives, incidentally, in the lower level of my house. She has her own apartment. That is her desire. Let's see. The President, President Reagan...or, Reagan, oh boy, am I behind on times, Bush, the guy that's there now, seven or eight years ago he started the President's Freedom Initiative which was to address the Olmstead opportunity for our country to have more people get out of nursing homes and out of institutions. It is noted that the state of Nebraska has never had an Olmstead committee. They say they address Olmstead with everything they do, but every other state that I know has Olmstead committees that have worked on this intensively. Okay, there's one answer that you didn't have. Let me just think of a couple more. I have no many notes, I can't believe it. There's a tremendous disconnect...the one lady that spoke who was the single parent, it is just horrific that someone like that does not have more help that they

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need and they have to make choices that they did. I mean there's respite care. There's all kinds of care and yet, because of inadequacies of service structures to tell people what's going on, it doesn't happen. Oh, I know, schools: You need to know that the schools are mandated. This is the big difference. Community-based services are not mandated. They could be. All that's mandated is you have a service coordinator, and what's the other thing you can have, you guys? You get to have two things. []

MARY ANGUS: Graduates (inaudible). []

PATRICIA MCGILL SMITH: Uh? []

MARY ANGUS: Graduates have an entitlement. []

PATRICIA MCGILL SMITH: They get what? []

MARY ANGUS: Graduates have an entitlement. []

PATRICIA MCGILL SMITH: Yeah. Oh. Oh, oh, yeah, graduates have an entitlement for a certain period of time after they graduate. They can get help to get into services. Those are the only two entitlements that the state of Nebraska. So is it any wonder, if there is no entitlement to services? And I'm going to just say it the way I see it. The state of Nebraska, and this isn't just this administration, it's a bunch of them, they have just squeezed and squeezed and squeezed the service structures in the community. They have not squeezed and squeezed Beatrice. Beatrice's money has gone up while ours has gone down per capita. And that has caused a tremendous problem. I couldn't believe that I figured out that I got more services for Jane in Virginia, which was, I thought, the worst place that ever had services in the community (laugh), and I've had to fight for almost everything that Jane has, and fight I do and I'll continue. But I need to tell you that...oh, my last thing. We have gone to the state and we have proposed that there would be some kind of working together of the parents and people in Arc to work

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and to try and help the parents and the people coming out of the institution. I did this years ago. I trained older parents and pilot parents to be willing and ready to be able to work with people in the...to move from Beatrice into the community, and it worked. It worked. I can tell you the two ladies, they were fabulous. They did a great job. I learned last week that they want to have this kind of help to the people that are going to be transitioning out of Beatrice, but they're going to have the service coordinators do it and if there will be some volunteers to help. Well, that sounds like a great plan but I must say if there is not some kind of training for the people who are trying to do this helping, that's a bad...that's a bad recipe. And so I would just urge that we take a look at trying to urge the state to pay particular attention. Because you cannot have people trying to help the folks, as you've heard them today so passionately speak about their needs for their children, and have people from the community, if they are not trained. Because the worst thing you would ever do is be judgmental of these parents or if you didn't understand where they're coming from. And so I just add that because that's something that the Arc would want to do but we will not put our people in a position where they are not trained and really ready to be able to help in the manner that possibly they could. And so on that note, oh, on ITS, ITS and the...that's a support for the community as well as Beatrice, and when the lady said that sometimes the people just move over and stay and that the communities don't want them back, that is a very hard indictment of the community services, because they don't think there is enough money to serve the people. The ICAP is limiting. CAP means cap, cap, cap, that's the way I interpret it. And so if the money is limited and you don't have enough money to give 24/7 or you don't have enough money to do a one-on-one--when we had that bad incident here in Lincoln it was supposed to be one-on-one services--that is part of the problem. And so I wrote the word down here, Solomon, and so you all are going to have to have the wisdom of Solomon to try and figure this out, but there are pathways that have been done in numerous states: Massachusetts, New Hampshire, California, Michigan, Minnesota. I can tell you, I've given you, Steve, all the documents the other day of exactly how states have gone about this, and it has not been horrible. It has been good. It has been good. But the state of Nebraska has to step up to the plate and the legislators are going to

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have to step up to the plate with the financial support in order to get this to happen. And my last note, one more thing, you asked the question, is there enough money in the system? I am appalled that we're keeping Hastings open with, what, 14 people out there and 43 people? A whole institution for less than 60 people? You've got to be kidding me. I mean, you are the stewards of money. You are the stewards of our taxes. I know it's political. I don't care. I, frankly, don't care. Norfolk, they're going to keep Norfolk open because they're going to make it into something else. Do you not understand that you're spending way too much money to serve too few people? So you close the darn institutions, and the same thing with Beatrice. Beatrice's budget last year was \$52-something million. I think it's slated for \$47 million or \$48 million this year. I think Mr. Wyvill, the...if you did the division it would be \$190,000 per person at Beatrice. You've got to be kidding. We're going to continue this? And I'm not trying to give the people sitting behind me a bad time. I just want people...I've never argued on money in my whole life. I argue on philosophy and rights and civil rights of people. I'll argue on money today because you are the stewards of our taxes. And I don't know how you can continue to keep something going that is at that ungodly amounts of money and think that that's okay. My daughter's services, incidentally, probably in-home/work support, I think she gets about \$28,000 or \$29,000 a year and it's because I provide quite a bit of support for her. She lives downstairs at my house. Any questions? And am I passionate, Steve? Yes. []

SENATOR LATHROP: Yes, you are, and it's good to have you here because, you know, you give us a perspective that's important to this process and I greatly appreciate it, as I do the information that you gave me and the time that you and I have spent talking about these issues outside of this forum. We'll see if anybody has any questions. Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Patty, you are really excited about the community-based services I gather, we gather that. []

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PATRICIA MCGILL SMITH: You darn betcha. []

SENATOR STUTHMAN: The problem that I have, you know, with Nebraska, we've got all of our population, Omaha and Lincoln area. And out west, Columbus, you know, further west than Columbus, you know, you get up to O'Neill, Valentine, up that direction, how can we provide a community-based service in those remote rural areas? []

PATRICIA MCGILL SMITH: Oh, I think you can. You're already doing it. You have the regional programs all over the state. Columbus has them. O'Neill has them. Valentine has them. Grand Island has a large amount of services. Kearney has a large amount of services. I can't give you the numbers. There's probably people in the room that could give you the numbers, but there are literally hundreds of people being served. Now there is one problem and this is something that has to be worked on. The people who have higher medical need, let's say, you know, that possibly they need more medical service, they might not be able to go back to Scottsbluff or Ainsworth if they can't get the help that they need. They may have to live in an area that, you know, psychiatry, psychology...I mean, I gave you the list for Jane. And incidentally, I have found that some of these doctors and the people that serve my daughter are absolutely the top in their field. It's hard to find them. You have to work hard to get them but, by cracky, they are not not wanting to serve her. They're fabulous. So, I mean, this idea that we can't find people to work, it took me some doing to do it, and I would help anybody. Oh, that's one thing I didn't say in my testimony. I will help the state get to be where they need to be. I will help any parent. I've helped hundreds of parents. I will help them to figure out how they can get their services and I will teach them. You asked whether the Arc teaches. We teach about advocacy. We will teach parents how to advocate in the community, how they will try to work to get the state to understand we need more money in community services, because we need to strengthen the community services. This has been one of the...it's been a "ch-ch-ch dun-da-dun." And the state, I'm sorry, I've done a lot on whether the service...I mean, Jane gets 27 hours a month work

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support. That is not enough, you know, and we need to get people to understand this. I mean, it's really hard to sit with a bunch of people sitting behind me that their people are being served at these huge amounts of money and my kid can't get ten more hours to help her go to her job every day. I mean, there's an imbalance here and we need to solve it, and you all have the best chance that we have ever had because it's like a crisis beyond any crisis we've ever had because they're pulling money away from Nebraska. DOJ is, you know, looking down your shoulders and over your heads. The community services are stressing. I mean there's just...it's like a...it's like a conundrum, but it can be solved and there are states, I am telling you, there are places that have gotten through this. They've written papers about it. They've told you how to do it. They've researched it. They've...I mean, let me give you one quick story, and I talked to this father. His name is John Clark (phonetic) and he told me I can talk about him. John Clark had a daughter names Gina (phonetic). Gina is one of the first children that ever came back from Beatrice. She was put in Beatrice when she was probably months old. She came out when she was about, I think, three or four years old. She went to the Maximation Unit for children. Gina laid flat on the floor. Gina did not walk, talk, feed herself, toilet herself or anything in the whole wide world. And John Clark, if he could have come today, said he would testify that absolutely the best decision that was ever made was to bring Gina back to the community because they could go see her every day of the week and twice on Sunday if they wanted to. It got to the place where Gina recognized them when they came in. Many, many people got to know Gina and Gina became a part of a community, even though she was extremely...she's the most disabled person I ever knew. And John told me I could talk about it before this committee. I didn't write it, but he said I could talk about it, because Gina is a person who was severe/profound, profound, profoundly disabled and was served. And I asked Bob Brinker. Yes, they still have the medical units. Yes, they have units that support people. People don't know this. Bob Brinker talked to that day about it, and a lot of the other service units. Now you asked the question about across the state. It is harder. It is harder out in the state if you have very, very complex needs. And I subscribe to the idea that either someone at Munroe-Meyer, they go across the state and they have

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(inaudible) that they help people. I subscribe to what has happened in Beatrice when they had people that worked out in the community, because getting help for behaviors is one of the toughest ones. And the lady and the man talked about every 30 days they would check to make sure that the gains that they had made with behaviors, if we had not had people to help my Jane with her behaviors she might be in jail or she might be dead. I don't know. I'd be dead trying to take care of her because Jane's behaviors have really been tough, if you know autism and you know compulsive behaviors. And I am telling you, she lives a wonderful life because she is supported. []

SENATOR STUTHMAN: Patty, and the reason I ask these questions as far as the community-based services, and I'm very supportive of community-based services,... []

PATRICIA MCGILL SMITH: I know you are. I know you are. []

SENATOR STUTHMAN: ...but as an individual that was a part of the mental health, the regions and... []

PATRICIA MCGILL SMITH: Uh-huh. Oh, the mental health reform? Yeah. Yeah. []

SENATOR STUTHMAN: ...and on that reform there and seeing what had happened when they released some of them and where they ended up, and I'm very cautious as... []

PATRICIA MCGILL SMITH: Oh, and well you should be. []

SENATOR STUTHMAN: ...as to, you know, not just closing the door and... []

PATRICIA MCGILL SMITH: No. No. []

SENATOR STUTHMAN: ...sending them out with a bag full of medications and find your

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own service. []

PATRICIA MCGILL SMITH: Right. And the Arc has never suggested that. The Arc has always said, and people leave out the one word, systematic, systematic deinstitutionalization. We...when we called for that two years ago publicly, we asked for it because of the first report that came from CMS. We asked for systematic deinstitutionalization. It's in my notes. Had you done that then you would be out of a world of hurt that you're having right now because you would have moved in that direction. And not having moved in that direction, now we've got all this stuff going on and it's not easy. It is not easy. And you're right. If you dump people in the community, it's the worst thing you could do. []

SENATOR STUTHMAN: And they end up in a prison if they have... []

PATRICIA MCGILL SMITH: They end up somewhere, not the place you want them to. []

SENATOR STUTHMAN: And that's what I want to be very cautious of... []

PATRICIA MCGILL SMITH: Yeah. No. No. []

SENATOR STUTHMAN: ...mainly because I have seen what had happened with that situation. I am one that, you know, I think that we need to move these people out, if possible, but not move any more in, you know,... []

PATRICIA MCGILL SMITH: Oh. []

SENATOR STUTHMAN: ...just like with the mental ones, you know. Keep them in the community to start with. []

PATRICIA MCGILL SMITH: Right. []

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SENATOR STUTHMAN: Never let them get to that institution. []

PATRICIA MCGILL SMITH: Well, and one of the things that's very frustrating for the Arc, I've tried to get many of the young parents to get interested in this issue. They just go like, my kid is never going to go there. We're...they just act like it's not there. But when they get a kid 18 or 21, they're going to find out like, oh, I think I should have been working on that, you know? []

SENATOR STUTHMAN: Yeah. Thank you. []

PATRICIA MCGILL SMITH: You're welcome. []

SENATOR STUTHMAN: Thank you. []

PATRICIA MCGILL SMITH: Anybody else? []

SENATOR LATHROP: I think that's it. []

PATRICIA MCGILL SMITH: Thank you, Steve. []

SENATOR LATHROP: Thank you. You'll be the last witness for the morning. Just so that we have an idea of what our afternoon looks like and how much time we might be looking at to hear from everyone else, can I see a show of hands of folks who intend to testify but have not yet testified? So five, five or six? Okay. Very good. Thank you. We'll see you back here at 1:30. []

RECESS []

SENATOR LATHROP: (Recorder malfunction)...start with our next witness. []

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LYNDA SWANSON: Okay. I'm Lynda Swanson. I'm from the Norfolk area. My son has been in Beatrice for about two years. I started out...I'm basically going to kind of give you a summary of where we...from the beginning. When he was three, he was diagnosed with being mild to moderately retarded. It took me making doctors angry in Norfolk to get him to Omaha to be tested to find that out. When I got back into Norfolk with him, they did get him right away he started at Head Start in Norfolk right away. He was in Head Start until he got to kindergarten. And the only school in Norfolk that was actually suited for his best interest was Bel Air in Norfolk. The teacher up there worked wonders with him up until he was of age, before he went into sixth grade. And then he went into the middle school system. Things at that point started changing a little bit, behaviors started showing up more. He was considered speech impaired, too, where he wasn't able to talk real well or communicate real well. They...and the behaviors just kept getting worse because I think it had a lot to do with probably because he wasn't able to communicate and express himself when things weren't right. After he got through his middle school years, he went into the junior high and then it really got bad because the resource teachers treated him like he was a two-year-old. They'd take things up to him and say, well, hey. When he was having problems, they'd take teddy bears up to him and say, you want to play with the teddy bear, little things like that and it just really set him off. He just...I mean, he tore the resource room apart. I was up there probably three to four times a week because they were having problems with him. It finally got to the point there where they had to...the principal there said, well, we can't deal with him anymore, we can't have him here because, you know, because of his behaviors. When he turned 13, he was placed at Envisions in Norfolk and I had to actually go into the court and turn him over to the state in order for that to happen because I didn't have the funding to pay for what he needed. And the Envisions at that point it just started, they hadn't been really in place that long. It worked out really well for a few years until he got a little older. The school system, I was still struggling with them, and finally it took...I had the school board in Norfolk with Envisions and sat down with the staff of Envisions and actually started a school in Envisions for the handicapped, for kids that couldn't function

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in the public school system. He was in that program until he graduated. Well, no, he was actually he was still...he was in there until he turned 19, and handicapped kids usually stay in the public school system until they're 21. When he turned 19, I had to go back into court and basically take custody because once he's 19, the state's no longer in the picture. Well, they're still in the picture, but just a guardianship of him at that point. And throughout that process there was instances in the settings out in the community where staff...you ask them questions, the part that really frustrates me in the community settings sometimes is you ask staff questions and they look at you like, well, I don't know. It's like, why don't you know? You're working with my son, you should know when I ask you a question. There was two instances where there were sexual abuse involved in that situation. The same child, the first time they removed the two, they separated them, put the other one in another home. And then within a month or so, they had them back in the same house again, and then it happens again. It's like, I went in and actually...I mean, the staff that were involved were fired on the spot. I made sure of that. They had tried to...I mean, they're sitting watching TV and not paying attention to what they're supposed to be doing. These kids are in these homes because they need to be in these homes, and this staffer is supposed to be doing their jobs. I had staff that were very familiar because I spent...I sat on the Envision's board when he was there. I went to the home quite frequently just to check on things, just popping in out of nowhere sometimes just to see what was going on. I had staff that would actually come up to me sometimes and tell me things that were going on that I wasn't aware of. I thought, well, I'm on the board, I should know what's going on. Well, there was things they weren't telling me. Once he turned 19 and I took over the guardianship and his financial part of it, Envisions didn't want anything to do with us anymore. I think...I don't know if it was because I had more power now because I was in that position or what. But they said, well, we can't serve him anymore, so you need to find another placement for him. We looked all over the Norfolk area in the area where I was at and there was nothing for him, nobody would give him a chance because of his behaviors and things. And they had his medication, he'd been in and out of the psych ward up there like probably once a week for a while there, and they had his medications so messed up that he was a

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mess. Nobody could work with him to help him because he was self-abusive and he'd hurt others. And there was a staff member that was in Envisions that was really, really close to him that she tried to stop him from going outside and he beat her to a pulp. She looked like she'd been in a domestic fight. And that's one thing with my son that you can't...when he's angry, you can't step in front of him because he just...it's like he blacks out when he gets that mad. He isn't aware that he's hurting somebody. Well, once they decided that they weren't going to help him anymore, we started looking and there was no...all the places...there's places in Norfolk, but none of them would help. Finally, there was a place in Lincoln that said they would help and we got him there and he got settled in and everything as fine for a while. And the medications and stuff were so messed up that they couldn't help him. And we'd been looking at Beatrice for a long time, but we were just having problems getting him in...getting him the help he needs. And finally it took, I mean, it took me and other team members and stuff and social workers and stuff, and finally we got him in the door. It was a blessing for me to get him into Beatrice because the staff were there and the doctors and the nurses and the people that could monitor his medications and maybe get him straightened out, you know, where he can function a little bit. His favorite things are movies and DVDs, DVDs and Christian Music. He's a Christian music crazy person. He just...that's all he talks about, wanting to go see the bands. Or if there's certain movies he likes, he can sit down and tell you about pretty much what the movie's all about, and by the time he gets done, you wouldn't be able to...you wouldn't want to buy it because you'd already know all about it. He can do that. It's just...and it's tough. I had to...having to give up my rights when he was 13. I knew as a parent if I wouldn't have, he wouldn't be where he's at today because there was a lot of things as a parent you want to hold back from your child, you want to protect them, you don't want anything to happen to them. And that's probably what it would have done. I'd have smothered him, you know. Today he's able to, I mean, he can communicate with you. It's tough for him sometimes to get out what he's trying to say, but he can talk to you now and he couldn't do that before. He can go out into the public sometimes and just be able to do things that he couldn't do before. Before, he could go out in a store or something, if he got near videos and movies and

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stuff, he had a behavior because he wanted those things. He wanted...he obsessed over things that people wouldn't think was a big deal. There was instance of cops. There was...in a video store or whatever. He wanted a certain thing and they couldn't have it and the staff were trying to redirect him and try to help him. And the person in the store automatically calls the cops. They told him he's okay, we can deal with this. But they automatically call the cops. The cops come in, basically don't even ask any questions, just roll him, cuff him, and pull his arms up behind his...up like this and take him to the cop car, don't even, you know, don't even ask questions. Well, is this person handicapped or something like that, didn't even say anything to him. And it scares him. Cops today still sometimes make him very nervous. He doesn't like being around them because of that. I know being at Beatrice has made me more relaxed. I know when things are happening, they call me. After an incident, if there's got to be a meeting, then I'm immediately called. If there's a medication change, I'm immediately called. They keep me informed about what's happening with him. Every day that I talk to him, he calls me everyday and he always asks me when I'm coming home. I wish I could have kept him home when he was a child. Financially, I couldn't. I would have dearly loved to have the avenues to do that. Still today it would be good, but the way this society is financially I'm not made of money and I can't, you know...and he needs around-the-clock supervision. He's a runner. He gets...I mean, he loves to go and talk to people. He'll just walk up to somebody and say, hello, my name is so-and-so. I mean, and he's a very happy person when things are going right. And if it wouldn't have been for Beatrice being there when I needed them, I don't know where he'd be. []

SENATOR LATHROP: You're satisfied with the care he gets there? []

LYNDA SWANSON: Yes. Yes, I am. []

SENATOR LATHROP: Very good. Well, thank you for your testimony. We'll see if there's any questions. I don't think so. Thanks for coming down. []

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LYNDA SWANSON: Um-hum. Okay. []

SENATOR LATHROP: We appreciate it and you're experience too. []

LYNDA SWANSON: Yeah. Thank you. []

JACK NICHOLS: (Exhibit 10) Good afternoon. Thank you for holding these hearings and I'll do what I can here. I got a couple of things I'd like to say. It don't make sense, but it will. []

SENATOR LATHROP: Maybe we'll have you start with your name. []

JACK NICHOLS: My name is Jack Nichols. []

SENATOR LATHROP: Okay. []

JACK NICHOLS: I live in Omaha. My wife and I have a son at BSDC. Please let me say two things and I'll tie them in connection to today's hearing. Many of us have heard conversations about pain of childbirth. You have to experience to really know, such as what we're doing here. Another one that's off the wall, on a dark night, a man walking through a cemetery fall into an open grave. After trying to crawl out, he gave up. He laid down in the corner and fell asleep. Soon after that, another man fell in the same hole. He struggled to crawl out. Making enough noise, he woke up the first man which in turn stood up and tapped the second man on the shoulder and said, they will come for us in the morning. The second man made it out very quickly. Thus, here we are being tapped on the shoulder and it's time to make it work. Like the witness in the pain delivery, it's hard for me to tell you what a parent goes through with their special needs child. I can tell you of our travels, fear, hope, disappointments. In Omaha, we have experienced St. Joseph's Mental Center, which is closed now, Richard Young's, which is closed now and I believe it's reopened now for a temporary fix instead of taking them to the

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emergency room. Immanuel Hospital has a unit there, and it's five days and you're out. Douglas County Health Center, he was a resident there for three years, but determined not compatible with our needs and the mental ward kept him for five days and out. We've experienced a group home in Kearney. Wow! What a shame our mental health in Nebraska. That was the closest to Omaha that would even try our needs. But when things got bad there, they had just called the police to help them because they used, for the night staff, would be students and they would talk about their dates. And this all disturbed me and needed a listen to. Then when money gets tight, send them to Richard Young in Kearney, then to Norfolk. We've experienced Norfolk Regional Center a few times, three or four, I don't remember exactly. It was a warehouse for the needy with few group sessions, maybe a walk-around campus. It may be closed by now. We've experienced Lincoln Regional Center because Norfolk Regional could not handle the challenge. Yes, forensic building where they bring the killers for testing. Wow. What peers. Lincoln Regional has a wonderful staff, including the late Dr. Martin and social working Stan on the fifth ward who with the communications as social services Mike Cool got us here where we are now. Beatrice State Developmental Center has it all. They have the staff that have the love for their job. Who else would do this for the money they get? We have seen great structure which keeps the residents active, such as movies, bowling, exercise every morning, jobs on campus, outings, classes for self-worth and proper behavior, meetings with the staff members to cover all aspects of the developmental, physical, and mental needs. Always, including we as guardians which I am so disappointed that the years of our worry can be overruled because of someone that don't know the person needs space. Thank you for taking the challenge of trying to understand the workings of this special, special needs person. Like the analogy of childbirth, it is very hard to paint the travels other people have gone through. And now the worry of the unfairness of folks that are being moved to community-based homes that may or may not fit their needs. No way the quality given at BSDC and of course the fear that places can terminate at will, especially when the one-year guarantees funding runs out. Thank you. []

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SENATOR LATHROP: Thanks, Jack. Anybody have any questions? Senator Stuthman.
[]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Jack, you had experience, you know, this situation where you...was this your son? []

JACK NICHOLS: Yes. []

SENATOR STUTHMAN: Was at the Norfolk Regional Center? []

JACK NICHOLS: Three or four times. []

SENATOR STUTHMAN: Three or four times, and they could not help him there or what was the problem? []

JACK NICHOLS: They actually kicked him out, transferred him to Lincoln Regional for the forensics...just what's wrong with this guy, you know, because of his anger. He was born fine and at three years...about three and a half years old he developed a hand-foot-mouth disease with a real high 105 degree temperature. Shortly after that, he started seizures before he went to school. But we got him into school and the seizures increased no matter what the doctors did. And then of course with the peer pressure of stay away from me, you know, I don't want to get what you've got, anger come in and it got to the point that they put him into special ed and real good clear through high school. I mean, it was tough. But as soon as he graduated from high school, we're done, find your own way. So we ended up calling the police and they took him to St. Joes Mental, and they said, hey, he's 19, he can walk. So we had to get an emergency guardianship and it just...they sent him to Norfolk again. It's just been a roller coaster and John has gone two years now. This is how long it took us to get to Beatrice. And about a year into it, they had ten months of anger-free, they have found the magic. But now they're taking kids off of his unit which makes him feel uncomfortable. And they've

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been talking to him about moving, of course, and he really likes it where he's at. And another thing, Mary mentioned something about there's nobody here from Beatrice. Maybe if the employees get done early enough, you can pull some of the people in to testify or maybe go around and talk to them. The residents, as I think you're going to find, most of them are happy there. Of course with anger management, that varies from day to day. []

SENATOR STUTHMAN: Um-hum. Well, the concern that I had and the reason that I asked you a question, Jack, is because, you know, the mental part was the Norfolk institution is where it's at. []

JACK NICHOLS: Right. []

SENATOR STUTHMAN: But you are so much more satisfied at Beatrice then with that type of a situation. []

JACK NICHOLS: That is...don't even describe how thankful we are. And I call it a campus. I notice everybody's throwing around an institution. It's a campus. It's huge, everything is there. []

SENATOR STUTHMAN: Um-hum. []

JACK NICHOLS: It's not an institution. Norfolk is an institution. []

SENATOR STUTHMAN: So by having him there, you're satisfied and it is accomplishing his need also. []

JACK NICHOLS: Absolutely. []

SENATOR STUTHMAN: Okay. []

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JACK NICHOLS: He's told us over the phone, thank you for sending me here. And he's...everything's there. They take him to Lincoln to the football games. I mean, he's got to come up with the money to pay his own way. They take him to Lincoln sometimes for supper. They take him to movies Tuesday nights off campus. He has three jobs he does. And it may be meaningless to some people, but they started a new program there and he has expressed that he wanted to be a mechanic. So they started a brand new program, never happened before, that he goes out in the morning and checks a vehicle over. He has a check sheet. Check the headlights, taillights, turn lights. You know, he don't drive it because he can't drive, but tire pressure, tire depth, and he loves it. When he's done with that, he goes in the...they have a deal for lawn mowers, a contract with some lawn mower company where they package up so many washers, so many bolts and nuts. I don't know what all, but he does that. And then in the afternoon, he delivers the paper. Now of course it takes two staff members to go with him because he's on risk alert. But I don't think you're going to find that at a community-based service. I know in a community-based, if you didn't notice it here today, I won't say a whole thing other than if my son would say he needed to go to the rest room, somebody would go with him and wait until he's done and come back. I've seen it happen and I worry about one person saying they've got the phones here. Is that child left alone? Beatrice won't let my son be alone. At night, he's in a double room with somebody else. But still, they go in every 15 minutes or so and check on him. []

SENATOR STUTHMAN: Okay. Thank you very much. []

JACK NICHOLS: Sorry about that. []

SENATOR LATHROP: Any other questions? Doesn't look like it (inaudible). Thanks, Jack, appreciate you coming down today too. []

JACK NICHOLS: Appreciate you having us. []

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BRAD MEURRENS: (Exhibit 11) Good afternoon, Senator Lathrop, committee members. For the record, my name is Brad Meurrens, B-r-a-d M-e-u-r-r-e-n-s, and I am the public policy specialist for Nebraska Advocacy Services, the protection and advocacy system for Nebraskans with disabilities. I am pleased to speak before you today and wholly support this committee's intent to fulfill the state's moral and legal obligation to protect the human and civil rights of vulnerable persons who are in its care and custody. The evidence is clear that Nebraska failed and continues to fail to provide for the safety, appropriate habilitation, and placement in the most integrated setting. We remain hopeful that the result of the committee's work will achieve such an outcome. As we have recommended in our report, An Indictment of Indifference, state officials should conduct independent comprehensive evaluations and objective assessments of all individuals at BSDC and prepare a plan with time lines to significantly reduce, by placement into appropriate community settings, the current population to a level consistent to meet the habilitation needs of the people living at the facility. Pursuant to an access agreement with the Nebraska Department of Health and Human Services, NAS staff is present at BSDC twice a month to directly observe the treatment of residents. Based on our observations and review of documented BSDC internal investigations, several continuing problem areas must be brought to this committee's attention. First, although the total number of reported abuse and neglect incidents has decreased somewhat, the severity of abuse and neglect incidents remains significant. Second, BSDC staff often do not receive adequate training and often are not aware of proper agency protocols. Third, accountability at BSDC is problematic. The investigations suggest an unwillingness on behalf of some administrative officers to act on, and staff to corroborate, reports of abuse and neglect. Fourth, devaluation of BSDC residents is common and reinforced through the abusive and offensive language some staff use when instructing or interacting with residents. Documented in the internal BSDC investigations are instances where clients are called filthy names. See incident 3 and 7 in the written testimony that I've handed to you. These instances and many others throughout BSDC investigations further document the need for a significant change in

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the organizational culture at BSDC that is based on respect for and valuation of people with developmental disabilities. Abuse and Neglect: As figure one demonstrates, BSDC residents are still subject to substantial incidences of abuse and neglect. According to the internal BSDC investigations and our analysis, there were 57 cases of founded abuse or neglect from September 2007 through July 2008. Now, we do not contend that every staff member at BSDC is abusive to residents. However, the number and types of abuse and neglect instance, whether founded or unfounded, remains alarming.

Examples of recent instances include: physical and verbal assaults on residents by staff; staff not intervening when witnessing staff-on-resident assaults; delayed reporting of injuries to residents; staff attempting to cover up or deny incidents took place; staff attempting to coerce silence on part of abused or neglected residents; and neglectful supervision of residents. And these claims are all documented in the written testimony that I've handed to you in more detail. Staff training: Based on our observations and the investigations, some staff are inadequately trained to work with residents at BSDC and others are unaware of or ignore the proper procedures and protocols established by the BSDC administration. Examples of instances of inadequate training include: improper care of residents; staff not current with CPR certification or performing CPR when necessary; and staff performing techniques for residents unauthorized by the BSDC human rights committee. Staff training is critical to changing the organizational culture at BSDC. To that end, we strongly recommend that social role of valorization become a mandatory part of the preservice training requirement of all staff working at BSDC.

Accountability: In order to provide the best quality care for residents in the 24-hour care and custody of BSDC, it is imperative that the BSDC administration take appropriate action to prevent and rectify incidents of abuse and neglect. Based on data from our observations at BSDC and the results of BSDC's own internal investigations, it is clear that the BSDC administration often fails to take appropriate actions necessary to maintain high quality staff or fail to remove staff found to be abusive toward residents. The investigations clearly show that some BSDC staff have continued to engage in abusive and neglectful behavior despite being reprimanded previously about treating residents with dignity and respect. For example in one incident, an individual who has

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had two confirmed allegations of neglecting residents. And in another incident a supervisor overlooked inappropriate behavior by other staff. Furthermore, our investigation or the investigations and our analysis has found instances where employees have chosen to quit working at BSDC because they feel the administration does not address the problem when transgressions occur. Based on our observations, investigations, and the CMS and DOJ reports, it is clear that it is time for state officials to act decisively to ensure that residents at BSDC are safe, receive appropriate habilitation, and are placed in the most integrated setting. I'd be happy to answer any questions the committee may have. []

SENATOR LATHROP: Senator Harms. By the way, I should have introduced Senator Harms who was... []

SENATOR HARMS: Late. []

SENATOR LATHROP: ...had a conflict this morning, but has joined us this afternoon. Glad to have you. []

SENATOR HARMS: Thank you, Senator Lathrop. Bradley, I'd like to ask you a number of questions. First of all, let's start with your statement that you talk about comprehensive evaluation in assessment by moving clients into a community setting. Do you honestly believe that we have a community-based program (inaudible) to address adequately these clients? []

BRAD MEURRENS: Some of them, yes. []

SENATOR HARMS: So some of them, yes. Give me an example. []

BRAD MEURRENS: Well, I would say there are community programs in place that could handle or that could take in residents that may not have a certain disabilities.

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They may not have overly profound disabilities. There are certain, you know, community agencies that can handle different levels of disability. So I think, you know, it...there are those community placements where persons that are BSDC could be placed with relative ease. []

SENATOR HARMS: That's part of my concern is that evaluation and appropriate assessment in placing someone in an environment without really knowing for sure whether that program is probably adequate and having the support services to be able to help that individual. I fear that we'll put them in a more difficult environment. So that's why I'm concerned about what you comments on that aspect of it. I want to talk a little bit about changing the culture. Let's talk a little bit about how do you see changing the culture of that environment? Because I agree with you. I just want to know what your views are in regard to that aspect. []

BRAD MEURRENS: Well, I think, you know, one of the easy...and easy way to start getting at the root of the problem is like what we've called for in our reports, Indictment of Indifference, is infusing social role valorization programs. An idea that people with disabilities have valued social roles and have value as a person. Infusing that theory and that curriculum into the preservice and sensitivity training that BSDC staff go through. Also I think that there needs to be quick and decisive action taken by administration when incidences of devaluation, either through language or through actions of staff, there needs to be decisive action taken, you know, for those individuals to stop doing that behavior or something to that effect. It's going to have to come from the top down. But I think that we need to start looking at the culture of the organization, and in looking at places where that culture can be changed. []

SENATOR HARMS: Yeah. So in viewing your comments, we really haven't addressed the other issue and that's management. I mean, when I look at all of this and I've read as much as I can humanly, possibly read until that I've been given, it boils down to the fact we have absolutely no management or the management is truly lacking there. Is

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that your observation? []

BRAD MEURRENS: Well, I think that's when we talk about accountability and the, you know, management looking the other way when instances happen, and documented instances of administration looking the other way and that can't happen. I mean, we agree. The management is a critical piece. []

SENATOR HARMS: Because without strong management, all the things we're talking about now will in fact not happen. []

BRAD MEURRENS: We would agree. []

SENATOR HARMS: Yeah, just will not happen I can tell you. I've been down this road before in another environment and I can tell you that unless you straighten that part of it up, we can do all the things in the world here but it's not going to occur. []

BRAD MEURRENS: We would agree. []

SENATOR HARMS: Okay. Thank you. Thank you, Mr. Chairman. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Brad, in your testimony here, and I'm going to dwell on a couple of issues here. On the staff training, and you state here where based on our observations. Give me a little bit of an example of your observations. Were you personally there? Was your group personally down there? Where did you get the information from? []

BRAD MEURRENS: I myself was not personally down there. But as we said earlier, we have an agreement with BSDC that we have staff that's down there doing those

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observations twice a month. []

SENATOR STUTHMAN: Twice a month? []

BRAD MEURRENS: Yes. []

SENATOR STUTHMAN: Okay. And you state there's been inadequately trained, you know...staff that has not been trained to work with the residents and are unaware or ignore the proper procedures and protocols. Explain that to me as far as what you think is inadequately trained. []

BRAD MEURRENS: Well, I think one example is the recent story about the individual that was having a heart attack, and the staff...there were three staff members who just kind of stood around and didn't perform CPR and didn't really know what the proper procedures were, called the, you know, emergency medical technicians. And we found that in the investigation as it says in the written testimony in more detail, there were like 99 staff that was overdue for CPR training and that's like the direct care staff. There were several other, you know, on call staff and other staff that were overdue for CPR training. There was an individual who authorized in a person's care plan and unauthorized technique which has to be authorized by the human rights committee that they never approved this, but yet it was...you know, this technique was in the person's care plan. So then again I think the incidents of staff being verbally and physically abusive to residents is another glowing example of inadequate training. []

SENATOR STUTHMAN: When you made the statement that they were overdue on their CPR training or update or recertification, these people had been, you know, have had CPR training, in other words, right? []

BRAD MEURRENS: I don't know. I didn't do the investigation. But that could be an assumption, yeah. []

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SENATOR STUTHMAN: I mean to me, you know, making the statement, you know, that they were overdue on it. Yes, they were overdue on it as far as paperwork is concerned, but if the individual had CPR training, he's still got CPR training. Whether he could do CPR tomorrow because his training was...his certification was over. []

BRAD MEURRENS: Sure. []

SENATOR STUTHMAN: I mean that's the situation that I'm a little bit concerned about. So but I, you know, I put a lot of trust and faith in individuals that come here, parents or guardians, and make statements of what's happening there. And I'm just a little bit concerned about, you know, you bringing these allegations here, and to me it's secondhand is what it is. []

BRAD MEURRENS: Right, but the allegations that I'm bringing to you are documented founded by BSDC internal investigations to be founded incidents of abuse and neglect. It's not just my word or something that I'm making up. These are actual documented founded incidents of abuse and neglect. Now like I said, I'm not going to claim that all staff are bad or treat residents poorly. I don't think that's true. There are certainly some and I think the 12 pages of the written testimony that I handed in, I think would speak loudly to that. I can't speak for the experience of all family members and all residents of the institution or facility. But I think that the numbers of incidents that are occurring that are documented and have been founded should give us some significant pause to reexamine these issues that I bring before you today. []

SENATOR STUTHMAN: Okay. Thank you. []

SENATOR LATHROP: Senator Adams. []

SENATOR ADAMS: Brad, you represent Nebraska Advocacy. So my assumption is

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you're going to advocate for anyone with special needs. Would that be correct? []

BRAD MEURRENS: We advocate for persons with disabilities, yeah, whether that be a physical disability, developmental disability, psychological disability, yes. []

SENATOR ADAMS: Okay. Good. The incidences that you bring forward I don't question whether they occurred or not. I guess what I'm wondering, and I realize that the charge of this group has been primarily to look at Beatrice, but we can't help but look beyond that. Are there incidences where your organization is called upon by parents and guardians of people who are in community-based programs needing your advocacy services? []

BRAD MEURRENS: I was speaking to our legal staff and our executive director, and they had indicated that we have had incidences where that has occurred and we have gone in and taken action against and advocated for persons who are being abused within the community settings, yes. []

SENATOR ADAMS: Okay. Thank you. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: Thank you, Mr. Chairman. Bradley, the information that you've documented here, if I recall, a lot of this is really supported by the federal review. You know, a lot of the things you've brought out are things that we have that were identified in the report that we've recently been given in regard to what the federal government...the feds have found. Is that correct? []

BRAD MEURRENS: Well, I think they're consistent with the reports and the findings of the feds. []

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SENATOR HARMS: That's the point I'm after. []

BRAD MEURRENS: But I think if I'm not mistaken the federal...the DOJ report, for example, came out I think in March, and these are up until July of 2008, several months after. []

SENATOR HARMS: The point I'm after, there's a theme that goes through this and it's consistent. []

BRAD MEURRENS: Yes, it is consistent. []

SENATOR HARMS: Okay. Thank you. []

SENATOR LATHROP: I do have a question for you. Senator Adams was asking you if you've advocated for folks in community-based care. You've seen similar problems in some of the community-based programs, am I right? []

BRAD MEURRENS: You know, I'd have to defer that to the legal staff. []

SENATOR LATHROP: Okay. []

BRAD MEURRENS: But... []

SENATOR LATHROP: Let me ask you this then. []

BRAD MEURRENS: Okay. []

SENATOR LATHROP: Do the community-based programs have the same level of scrutiny as Beatrice? []

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BRAD MEURRENS: To the best of my knowledge, no. But again, I would defer to the legal staff to really get that accurate answer. You know, we would be happy to engage in a conversation about increasing our role of to oversee or be that sort of watch dog group for more community-based residences. []

SENATOR LATHROP: I appreciate that and I think that would make people in this room more comfortable. Part of the problem is is that we seem to compare apples to oranges because over at Beatrice we have the Department of Justice, we have CMS, we have state regulators who are in there doing surveys and looking for violations. And we don't have reports of similar surveys that have been done in the community-based programs. So almost because there's a void when it comes to how are they doing? Is there abuse and neglect in the community programs? We're kind of start out by assuming that the troubles in Beatrice and everything's okay in the community programs. We don't know that to be true. []

BRAD MEURRENS: You're right. And we would be happy to engage in conversation about increasing our funding, state funds for to do some of that activity. We'd be happy to talk about that. Yes. []

SENATOR LATHROP: Okay. Thank you. Any other questions? Doesn't look like it. Thanks for coming down. []

BRAD MEURRENS: You're welcome. Thank you. []

SENATOR LATHROP: How are we doing for witnesses? Looks like we have...Joe, you wanted to take... []

JOE VALENTI: Could I respeak to speak to incident 003. I know you were questioning.
[]

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SENATOR LATHROP: That's...yeah. Let's have you sit back down and tell us your name again. []

JOE VALENTI: Joe Valenti again, V-a-l-e-n-t-i. You have incidence 003, which involves our son unnamed. And that incident did occur, and the only way we would have known about that incident and thank God for the Beatrice residence teenagers reported that incident at the YWCA. And I called that family and thanked them because I got it off the police report. So just to verify, Senator Stuthman, any of your questioning, not in a bad way. Whether or not this incidence occurred, I can verify with you that that incident did occur. And those employees were dismissed. I would like to address Senator Harms's question about management. You're right. You're not going to change the culture without changing management or at least adjusting management and management's philosophy. But with management as you know, let's just call it for the sake of discussion that you have first level management, you've got second level management in Beatrice, and then you've got maybe third level at HHS and/or fourth or fifth or whatever the case may be. And then you've the Governor. So I mean, again, it's a systematic problem as I stated before. And I'm sorry, I know you were tied up this morning, but you just can't start with Beatrice. You've got to start up here and work its way down because that's the only way culture is going to change in my opinion. []

SENATOR HARMS: Right. I don't disagree with that at all. []

JOE VALENTI: Okay. []

SENATOR HARMS: Thank you. []

JOE VALENTI: Thanks. []

SENATOR LATHROP: Thanks, Joe. []

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JOE VALENTI: Thank you. []

JUNE CLAPPER: I'm June Clapper. []

SENATOR LATHROP: We'll let you sit down and you can get near that microphone so we can all hear you, and then we'll have you tell us your name. Okay? []

JUNE CLAPPER: (Exhibit 12) Hello. My name is June Clapper. I have lived in the Lincoln Regional Center and went to the state home. I've stayed in Lincoln Regional Center for about four months. Then I went to Beatrice in 1964. I live in Omaha now. I'm...do stuff with the Ollie Webb Center too. So I worked at Methodist Hospital in Omaha for six years. And then I did all kinds of stuff. []

SENATOR LATHROP: Yeah. Go ahead and tell us what you... []

JUNE CLAPPER: I've known some people that live in Beatrice. []

SENATOR LATHROP: Okay. []

JUNE CLAPPER: And I lived there for six years. Then I moved to Omaha on a job...what do you call it...job placement, and then I got fired from there. So I've been doing other stuff. I've been to conventions out here at Kearney, Nebraska. I always went to the Crossroads to do my shopping for clothes. Then I went out there to Bag 'N Save to get my groceries. And then I've also been on the quality review team. That wasn't put in here. I have to...been to some of them homes where people stayed. There's a lady by the name of Cathy McGuire (phonetic) asked me if I'd join a review team. Well, I've been to some of them homes where residents lived. I've been through Omaha, Bellevue, Papillion. To me, I'd never go back to Beatrice. No way in hell! Because I've got relatives that live down there and there was relatives that worked at the state home. And I would ever go back there. But I know some people that lived in another home that

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was in Beatrice. It's called the other institution that they have down there. I've been around as long as you know when. I was born in 1943. My father had a heart attack in '61 and that's when I had to quit school. So I went through to sophomore year. When my father had a heart attack, I got taken out of school. []

SENATOR LATHROP: All right. We'll make sure no one has any questions. Doesn't look like it. Thanks for coming down. We appreciate it, Ms. Clapper. []

JUNE CLAPPER: Sure. []

SALVADOR GONZALEZ: Good afternoon. My name is Salvador Gonzalez. I'm from Omaha. I have a 48-year-old Downs syndrome daughter. Just to give you a little background, Sandra's (phonetic) mom and I was divorced back in 1972 and she took Sandra (phonetic) to Beatrice and left her there without my knowledge. And so I went to court, got the custody taken away from her. Sandra (phonetic) was the first one to come back, one of the first ones to come back out of Beatrice, you know, back in the last '70s because of the court order. The main reason why I'm here was because Sandra's (phonetic) hours that she's getting. The hours that she's getting was back...set her back in the late 1970's. She's got 25-hour day service hours and 124 hours residential hours. It's really difficult to get her into a decent placement because of the hours. When the providers looked at (inaudible) and they say, you know, how many hours she's got? Well, the first thing they say, well, we can't provide services because of this...because the hours she's got is not...you know, just can't do it with that. So back in April of '06, we took and put her in the ITS...I think it was the ITS program, they called it, Beatrice. Is that it? Did I say that right? And she was there for three months, and I was very pleased. I was very pleased with that program. Sandra (phonetic) done very, very good except that I wanted her home because Sandra (phonetic) and I had been very, very close. She spends every other weekend, holidays, just as much as she can, you know, I bring her home with me. So I want her to be home. But what is happened is is that she's had to get into services with roommates that are very, very abusive because of the

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hours. And that's the whole thing is it's all about the hours. She just can't go any place else, you know. So I've had her out of two different places I have had to take her out of. I'm in the process of taking out of another one now because of the abuse that goes on there. I didn't come down here to talk about that. But in listening to things that were said by some of the other people ahead of me, you can't just take people out of Beatrice and place them in home-based programs and then forget about them because that's what's happening in some of...there are some good programs. There are some good providers I would say. But like I said, Sandra (phonetic) has had to go with places where there's a lot of abuse. I've got pictures here that would contradict what this fellow here was saying about abuse that goes on in the residential settings. I didn't want to bring that up, but in listening to things, you know, there's the good, the bad, and the ugly. And I just wanted to have a placement for Sandra (phonetic) because Sandra's (phonetic)...I'm the only one Sandra (phonetic) has. She has no one else that's going to look after her. So I wanted her in a good place where she would...that I could be happy that she's going to be if something happens to me. I'm up in my middle 70s. And so, you know, I got to have some...want to be comfortable with some place. But with the hours she's getting, that can't happen. And like I said though is that I've always said when I started reading about the committee that was investigating Beatrice, I've always said that same committee has got to come and start investigating some of the home-based programs also because you can't just take them and walk away from them and think that everything is going good. You know, it's not, it's not. Believe me, it's not. I don't know. But the reason I came down here for was because I want to know is when are we going...when are you going to look at these people that have been out of Beatrice for all these years. And yet their hours have not changed. I mean 25 hours for a day service? Come on. You know, you can't...nobody wants to take them for that. So you know, that's my big question is when are you going to do something about that? That's all I have to say. []

SENATOR LATHROP: All right. We probably have some questions for you, and I know that you're explanation of your experience...first of all, your daughter, was she at

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Beatrice for a time? []

SALVADOR GONZALEZ: Back in the '70s... []

SENATOR LATHROP: When your ex-wife put her there? []

SALVADOR GONZALEZ: Yeah, she was there for two years. Um-hum. []

SENATOR LATHROP: And how old was she when she came out of Beatrice? []

SALVADOR GONZALEZ: Well, she was probably about 18, 19, something like that. []

SENATOR LATHROP: Okay. And since then, she's...you're involvement with the state in the provision of services for your daughter has been on a community-based program basis. []

SALVADOR GONZALEZ: Um-hum. Um-hum. []

SENATOR LATHROP: And when you talk about the hours, because I think Ms. Patty Smith talked about that as well, and that is you have so many hours. Does that go through the ICAP formula and then somebody says you get this many hours to work with and you can go get this much care for that? []

SALVADOR GONZALEZ: Yeah. Yeah, back at the first part of this year, believe filed a--I don't know what they call it--a grievance or something. So we come down to Lincoln and testified to try to get them more hours, but we were rejected. I think it was... []

SENATOR LATHROP: So the hours is sort of the credit you have to work with to go out and get services within the community. []

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SALVADOR GONZALEZ: Services for her, correct. []

SENATOR LATHROP: And your concern today that you've expressed to us is however they evaluated my daughter, they understated the hours she needs for services. []

SALVADOR GONZALEZ: But this goes clear back when she come out of Beatrice clear back in the '70s. I mean, come on. I mean, the Legislature has gotten wage increases in your wages, I mean, from over 30 years, over 30 years. You know. Cost of living has gone up and everything. I mean... []

SENATOR LATHROP: So what you're concern has to do with the number hours... []

SALVADOR GONZALEZ: Yeah. []

SENATOR LATHROP: ...they give you to work with to get the care. []

SALVADOR GONZALEZ: And you know I put the blame on the system because I'm saying is, okay, if she had more hours, then she could go to places that she could get better care instead of having to go someplace where there's abusive. When she has to go someplace where people have more hours, when you have people with more hours, then there's more problems. That's why they've got the more hours. You know. []

SENATOR LATHROP: And if she doesn't have enough hours, why does she have to go to places where people have a lot of hours? []

SALVADOR GONZALEZ: Because they won't... []

SENATOR LATHROP: I don't understand that. []

SALVADOR GONZALEZ: Because they won't accept her because they don't have

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enough...there's not enough...I can't explain it as good as probably the social worker did. []

SENATOR LATHROP: You're doing fine, you're doing fine. []

SALVADOR GONZALEZ: But the way I understand it is that they have to have enough hours in order to pay for the help and everything that they have. And so they have to have so many hours in that one unit, place. And she usually goes someplace where there's two other ladies, like there's three people. You know. []

SENATOR LATHROP: So whether you're a recipient of these benefits or a provider, hours become a commodity. []

SALVADOR GONZALEZ: Oh, yes. []

SENATOR LATHROP: And a provider has to have so many hours going on in a day of services in order to make ends meet. []

SALVADOR GONZALEZ: In order to make ends meet. []

SENATOR LATHROP: And so they have high-end people, and your daughter ends up because she's a low hours person... []

SALVADOR GONZALEZ: Because she's low, yeah. []

SENATOR LATHROP: I get it. []

SALVADOR GONZALEZ: I mean, that's where she's at today, you know. []

SENATOR LATHROP: Okay. []

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SALVADOR GONZALEZ: And it's just a matter of time because I can't keep her where she's at because of the abuses. I fielded stuff that's going on there. []

SENATOR LATHROP: And she's literally being physically assaulted by other residents. []

SALVADOR GONZALEZ: Um-hum, um-hum. []

SENATOR LATHROP: I got you. []

SALVADOR GONZALEZ: And when I talked to this gentleman here, I was talking stuff, like that, I did call his office and I did talk to them and they were supposed to get back to me. And I did explain what was going on and everything, and I never did get a phone call back. But I did explain to them about the abuse that I thought was going on. And I never got a phone call back from them, so. []

SENATOR LATHROP: You talked to other people who are users of the community-based programs? []

SALVADOR GONZALEZ: Have I talked to... []

SENATOR LATHROP: Yeah, other families. []

SALVADOR GONZALEZ: Oh, sure, sure. []

SENATOR LATHROP: So you are...you are the first one that's come in today with an experience about someone being abused in a community-based program, so I'm curious. Do you know of others with similar experiences or is yours an isolated one? []

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SALVADOR GONZALEZ: Well, offhand I can't really answer that question. You know, but I have proof to backup what I'm talking about. []

SENATOR LATHROP: Oh, I'm not suggesting that you don't or that I don't believe you unless you have six more families that agree with you. I'm just wondering if you had heard of other instances. []

SALVADOR GONZALEZ: Well, yes because I've known of people that have withdrawn people out of services because they were dissatisfied of what or how things were going on there. []

SENATOR LATHROP: Okay. []

SALVADOR GONZALEZ: So you know, where they have taken them back home or they've taken them and tried to get them into another provider, you know. []

SENATOR LATHROP: Okay. []

SALVADOR GONZALEZ: But just like I said is that I've taken Sandra (phonetic) and we've put her in the ITS program hoping that by the time she got out of...when she come through that, hoping that she was going to get more hours that would make her more attractive to a provider. Well, she did for six months, but then her hours went all the way back down to the original 124 and 25. []

SENATOR LATHROP: Got you, got you. []

SALVADOR GONZALEZ: You know, and that just... []

SENATOR LATHROP: We have some other questions. Senator Harms. []

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SENATOR HARMS: Thank you, Senator Lathrop. You talk about abuse and I'm assuming your daughter was abused. Is that correct? []

SALVADOR GONZALEZ: I'm sorry? []

SENATOR HARMS: Well, you were talking about abuse and I'm assuming that your daughter was abused. []

SALVADOR GONZALEZ: Yes. []

SENATOR HARMS: Okay. Did you file any kind of a complaints... []

SALVADOR GONZALEZ: No, no I haven't. []

SENATOR HARMS: ...about that or did you follow that up and ask for this to be stopped? []

SALVADOR GONZALEZ: You mean did talk to... []

SENATOR HARMS: Yes, did you file it with the... []

SALVADOR GONZALEZ: With the PS? []

SENATOR HARMS: Yeah. []

SALVADOR GONZALEZ: APS. You don't know how many times I have picked up that phone and dialed the number and didn't go through with it because I'm the kind of person who don't like to get people in trouble, and I was afraid of getting...I was hoping that for some way, some how I was just hoping...because I need someplace for my daughter to be. []

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SENATOR HARMS: So you were more concerned...you were afraid that they would probably mistreat your daughter? []

SALVADOR GONZALEZ: Yeah. I was the repercussion. I was afraid of that, sure. []

SENATOR HARMS: Or they might just move you out so you're on your own. []

SALVADOR GONZALEZ: Well, no not so much that. Some repercussion things may be going on that I'm not there that I don't see or hear about, you know. I mean some of the things that I do here or sometimes staff will say things to me about different things that happen, you know, where a staff might say, well, this other staff person...basically the abuse is not from staff people. It's basically from roommates, other people, and that's what I'm saying is that with the hours, she has to go to a place with other roommates that are higher hours, but they also have higher needs. And I've incidents where the staff would say, well, so-and-so was beating up on Sandra (phonetic) and I had to go in between them and intervene. You know, stuff like that, you know. And then when I bring this up to the management, well, then it always seems like it doesn't happen, it didn't happen. And then before I know it, that staff person is gone, you know. []

SENATOR HARMS: So you did really make a complaint or you did bring it to... []

SALVADOR GONZALEZ: To management? []

SENATOR HARMS: To management's attention. []

SALVADOR GONZALEZ: Yes, yes, yes. []

SENATOR HARMS: That's what I was really looking for. []

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SALVADOR GONZALEZ: But as far as APS goes, Adult Protection, no, I haven't. But like I said is that I wake up steadily at night and I think about and I wake up the next morning and say, I got to do this today, I got to do this today. And I've picked up the phone and dialed the number and I hung up because I just, you know, I just don't want...I did call the advocacy. I did all them. That's...you know, and they did, the lady that I talked to did instruct APS to report it. And like I said, if I hadn't done it, you know...
[]

SENATOR HARMS: Well, you shouldn't have to have that kind of fear. []

SALVADOR GONZALEZ: I'm sorry? []

SENATOR HARMS: You should not have to have that kind of fear because if something takes place, we ought to react in the appropriate manner, and your daughter and you should not be at risk. []

SALVADOR GONZALEZ: And but sometimes you feel like they're all alone, you know. []

SENATOR HARMS: I understand that. []

SALVADOR GONZALEZ: Just like the first lady that came in. I could relate to some of the things that she was saying, you know, because you're all alone. You don't get no help. []

SENATOR HARMS: That's what I'm saying. []

SALVADOR GONZALEZ: You know, where do you go? []

SENATOR HARMS: Yeah, that's why I'm saying you shouldn't have to worry about that. You should have the environment where you can actually have the freedom and the

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opportunity to make the complaint and it would be reviewed and investigated and dealt with. []

SALVADOR GONZALEZ: But who do you complain to, you know? Because you can say something, complain on something, and then management will come up with a different story because they can put down anything they want in the books and it's my word against their word. And then when I get to the service coordinator, then she'll say, well, they said this or they said that. Please, that's not the way it happened. You know, but you know, it's my word and it seems like the service coordinators always take the side of the managers. That's the way it always seems. And so then basically then you're all alone. You know, but I think that the hours, I think that that basically, you know, when I sit there and I think about the whole thing boils down to that and I blame the Legislature because they are not funding the money for Sandra (phonetic) to get decent care that she is entitled to. I feel she's as human as just anybody else and she's entitled to it. You know. []

SENATOR HARMS: Thank you very much. []

SALVADOR GONZALEZ: Thank you. []

SENATOR LATHROP: Thank you. Senator Wallman has a question for you. []

SENATOR WALLMAN: Yeah. Thank you for coming down. So you feel that the home-based care is not watched over close enough, you know, like the BSDC were pretty much watched over by, you know, by the Department of Justice. []

SALVADOR GONZALEZ: Correct, right, right. I think they should be watched over better. Yeah. []

SENATOR WALLMAN: Okay. []

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SALVADOR GONZALEZ: I mean, don't get me wrong. You know, I mean I know there's some good ones out there. You know, and I've been there when it was really good. But then I've seen it with staff changes and getting rid of...it seems like sometimes they get rid of the best staff, you know, and then it just goes down hill. It needs to be monitored. It needs to be monitored. Like I said, as I sat there reading...I read all the reports about Beatrice and I say, you know, they need to do the same thing with some of the home-based programs. []

SENATOR WALLMAN: Thank you. []

SALVADOR GONZALEZ: Thank you. []

SENATOR LATHROP: Thanks, Mr. Gonzalez. Okay. []

ANNIE ADAMSON ANDERSON: Hello, Senator Lathrop, members of the committee. My name is Annie Anderson, A-d...I'm sorry. I'm doing my maiden name. Adamson Anderson, A-n-d-e-r-s-o-n. I am the parent of a 21-year-old son named George (phonetic) who has a developmental disability. I am from Omaha, Nebraska, and in Omaha is where we have raised my son. I also have two other siblings. And today I just wanted to give you an example of some of the many community services that were out there from my son and still continue to be out there for him. I feel as a young man that we have gotten to a huge milestone in his life at age 21. Two months ago, he was able to move into an apartment on his own, which is something that we as a family have dreamed about and he as a young man has dreamed about as well. I would like to say that I don't think that that would have been a possibility considering the severity of his disabilities and what he was born with if we had not had all of the community services, the array of services that Omaha provide with us, to us. It was not always easy to find the services and that is something that we also need to work on. And when I was first presented after my son's birth with a place to make that phone call to, oh, you have a

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child born with a variety of different disabilities, here's a phone number that you may want to call. It was very difficult for me as a parent to make that initial phone call. I didn't want to be judged, you know, by these people. I wondered would they judge me for the decisions that I have made? Would they judge me for what has happened to my son and the kind of disabilities that he has. It was very difficult to make that initial phone call. But I believe that when I sat down and made that phone call, that a whole chain of events happened that has been very important in my life, as well in the life of my child. What I did was I opened a door and it was very scary to let all these strangers come into my life and my son's life. But I opened a door and I let these folks come in because the bottom line for me was that they had trained many more years and had much more knowledge than I myself had had. When I got pregnant and had my son, I had no idea that he would be born with so many different types of disabilities. No one in my family had ever encountered this before. When I was in college, I did take some classes and things about people with developmental disabilities, but again I said I just never imagined that it could happen to me. And so opening that door and letting these individuals come into my life was difficult for me. It was exceedingly difficult for my husband. He had always been born and raised thinking that we as a family can do this together, you know, we're going to be able to do this. We don't need to go out there and ask for help. And so it was a lot more difficult for him. But when we opened the door, we were pleasantly surprised to find that not only were there an array of services for my son George (phonetic), but also those people that were connected to those community services, they really are the people that have given us the information that we have needed. And I noticed that today during testimony you were hearing things about school districts. And I would have to say that the early intervention programs in a variety of different school districts in the state of Nebraska are absolutely excellent. As you move your way through more services as my child has become older, sometimes you do lose some of that excellence and you do see a slip in quality. And I attribute that often to the fact that people will buy into the philosophy that my son is a valuable human being. But when it comes to giving their dollars to support that for a lot of the community programs, sometimes they will say, yes, this needs to be done. But when they actually come to

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following up with the dollars, it does not always happen. But we are very happy with the services that we have received through the community. And I just wanted to end by telling you what some of those services are so you at least understand that there are many services out there. Obviously my son was born and spent 124 days in a hospital, so a lot of our services that we received were through some of the hospitals. And in the Midwest here, we are very fortunate to have some of the quality. If my son had been born anywhere else, the doctors had told me that there was a chance that he would not even be alive today. So we used services through the hospital. We used services through the NICU, which is a neonatal intensive care unit. And through that NICU we were introduced to a support group, and through that support group is when we began to meet other parents who then would network with other professionals. And we began to find out what kind of community services were out there for our family. So we went through the NICU support group and went onto another program called a parent-to-parent program. Right now I think there are 700 parent-to-parent to programs across the United States. In the state of Nebraska, we were fortunate enough to be one of the very first parent-to-parent programs. We've since won many awards for establishing these types of programs in the state of Nebraska. We have a lot of national attention over that type of thing. And in this program is where I began to learn more and more about what community resources were out there through the different people in the program, through the different type of service that it provided us. We used respite services when my son was growing up. We used psychological services as he was growing up. And keep in mind that as we were educating ourselves as parents and as we were trying to make sure that we were enhancing our problem solving skills in case they were ever needed, my son was also using occupational therapy in the community. He was using speech therapy in the community, physical therapy in the community. He also used eyeglass services. And at times it was very difficult for us financially. When my son came out of the hospital, he was close to being a million dollar baby. And my husband and I always thought that with my husband's good job that the insurance would cover all types of services and things that we needed. And unfortunately we found out that wasn't true. There was a cap on my husband's insurance policy, and my son went

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over the cap the first four months of his life. And so not to say that it was an easy go it. It was very, very difficult. And as a human being I think I learned the majority of my problem solving skills and how to make good decisions based on the fact that I had a child born with a disability. He went to the Omaha Public Schools. He received van services through the schools. My husband and I went to Health and Human Services several times to seek out financial assistance to help us in areas when we could not pay. We did our best as a family and as taxpayers of the state of Nebraska to pay everything that we possibly could to make sure that George (phonetic) got the kinds of services that he might need. We used the services at Munroe-Meyer where he went and had some testing done. We used the services at the parent training institute. It's called PTI Nebraska now. Each state in the United States has a parent training center where families can go and get information about educational services or those types of services as well. We were one of the families that learned about that and took advantage of all that type of information which greatly helped us as we went through our educational process. We also were involved in a program called the PRISM program, parent resource information and support meetings through the Ollie Webb center. And that's where we became more knowledgeable as parents about what services and things were out there. When we went to PRISM, which was offered every month, they would have guest speakers come in and talk to us parents on topics that were of interest to us: guardianship, financial assistance, where to go next for help, problem solving, social skills, those types of things, how do you talk to doctors appropriately, how to use the right language when you need to get a service and go in and speak the language that they would understand. We learned all of those things through the PRISM program. My son also was affiliated with the Ollie Webb Center. It used to be called Go Ark at one time. Through the Ollie Webb Center, we as parents were able to get support, and he was also able to go through a variety of mentoring programs called the just friends program. He went through best buddies, which is actually a national program. It's a Kennedy Shriver funded program. He was able to go through best buddies and make friendships. All along the way while we are getting this assistance and he is getting this assistance, we were asking my son, what did he want to do? What

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were his dreams? What did he want to seek out? We were able to listen to what my son said and definitely make some of our choices based on that. George (phonetic) will be getting involved in the ultimate life program, which is an adult program that will pair him up with a buddy to go do the things that as I age I'm not able to do with him. My son has a lot of value to me, and the society that I live in has a lot of value to me as well. I don't think I could imagine myself being here today talking in front of you if it wasn't because of all the other parents and all the other professional that took a chance on my family and my son. So I just wanted to give you a just a peek into when it works well in the community, it means that my son will probably be a very successful individual. I know that we have things ahead of us. I know that there's things out there that we have not personally experienced yet or encountered yet. But I also know that I have a personal board of directors that I carry around in my mind, and I built these board of directors based on meeting people such as Patty Smith, based on meeting people such as June Clapper who has a disability, based on meeting Ollie Webb who had a disability. I have gotten this personal board of directors in my mind so that whenever we need to solve problems or we need to look for services. But whenever there's not a service out there or whenever there's a service that needs to be changed or needs to be looked into that I have the freedom as a family to go in front of those folks and talk about what we need, and to maybe give you a little bit of information that you might need in your decision making. And so I think that we show an example where we have used an incredible amount of services in the state of Nebraska. Do we need to change how we deliver services? Absolutely, absolutely. I echo a lot of what was said today about needing some more oversight. And I think what it boils down to to me in a lot of cases unfortunately is the funding. We could do so much more in the community where individuals feel more comfortable. We could do more of those things in the community if there was more funding funneled in those directions, and I truly believe that. So when I look at Beatrice and I look at the situation, I can't help but look at how much it's costing for one individual as compared to what I have personally experienced by using services in the community. I also look often into what other states have done. And that would be my suggestion is that we look at what other states have done because certainly other

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states have deinstitutionalized their states and still been able to provide services in the community that were more than adequate. []

SENATOR LATHROP: Very good. Thank you. []

ANNIE ADAMSON ANDERSON: Thank you very much. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: I'm sorry. Thank you, Mr. Chairman. Annie, in regard to the services you have, are those services...how are they funded, do you know? There are probably a variety of ways. []

ANNIE ADAMSON ANDERSON: Oh, certainly. []

SENATOR HARMS: Okay. Do you know... []

ANNIE ADAMSON ANDERSON: Some of the services that we get are funded through the United Way. Some of the services that we get would be funded through the state. I know PTI Nebraska is federally funded. []

SENATOR HARMS: Okay. So I really impressed with the services, and thank you for sharing that because I did not have the background to understand that this many services were available. Now when you look at urban America and you're fortunate that you're in Omaha... []

ANNIE ADAMSON ANDERSON: Absolutely. []

SENATOR HARMS: ...because you have this services. This probably an unfair question and if you don't know it, it's okay. As you move out of the Omaha and the urban areas

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and you get into rural America, do you see these same services being available or all of sudden does it just narrow down and you don't have much left? What are your observations? []

ANNIE ADAMSON ANDERSON: My observation and my experience is that in some of the more rural areas, obviously you're going to have to travel further. I mean, I think that's just a daily part of their lives is that in order to get some of these types of services, they're going to have to travel. And I can't really speak to some of the exact services that I receive in Omaha, but I can speak to the parent-to-parent program and the parent-to-parent support that we had. That was really our initial point of entry into finding out all about the disability world and realizing we need to make a connection. I can tell you that there are many parent-to-parent programs across this state of Nebraska. And so that really was our initial point. And I anticipate by hearing some of the families today that perhaps they didn't have that entry into the disability world, whereas we did. But I do know in the state of Nebraska, there are parent-to-parent programs scattered all throughout the state. []

SENATOR HARMS: Thank you. []

SENATOR ADAMS: Any other questions? []

ANNIE ADAMSON ANDERSON: Thank you. []

SENATOR ADAMS: Thank you for your testimony. Is there someone else who would like to testify? []

JOAN OMEARA: I would like to say a few things before we close. []

SENATOR ADAMS: Please come back up and again restate your name for the record.
[]

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JOAN OMEARA: Sure. My name is Joan O'Meara, and I'm president of the BSDC Family and Friends Association. And we were not here, the BSDC people, to defame any community program. I'm on the Governor's committee, advisory committee, for DD. I'm the only one from Beatrice. The rest are all from community programs spread across the United...through Nebraska. We all agree that something must be done with the DD program. There has to be changes. One shoe does not fit all. I don't care...community programs are necessary, in-home care is necessary, and so is BSDC necessary. The mentality of the retardation is so long and so vast and so changed you can't say that someone at this end will fit into the shoe at this end nor can I say that this end is the only way that this should be here. I agree. There are some that need to live in community homes and wish to live in community homes. There are others who can't. They can't speak even. And we have to make as parents choices. And one of the choices should be the fact that there is this large spread of availability for DD people, and that we could be picking out where our child is best suited. Right now, my child is best suited at BSDC. She's been there for 44 years. To change her would be detrimental. She calls that place home. I take her out every week to go to eat. We eat in the car because Cindy (phonetic) is in a wheelchair and I can't handle picking her in and out. And she loves McDonalds. So we go to McDonalds. The minute she is finished eating, she said, I go home. And that was the only word she can say, and momma or Pat (phonetic), her brother or Cat (phonetic), her sister Cathy (phonetic). Otherwise Cindy (phonetic) does not speak. She speaks with her hands, like her mother, so that we are able to understand her. But what I want you to all get out of this is not that we have two camps here. We don't. We have one united camp. We need to work for developmental disabilities that Nebraska is the best in the nation, and our hope is in you. You finally have heard our voice. You have no idea how we have cried about the injustices that were going on. And I didn't want you to feel that we're tearing down one program for another. We're just citing where it fits one, it's not fitting the other. So I thank you for you time, and I call you the "magnificent seven". I don't know of anybody that would walk in through a wall of fire and that's about it. Thanks so much. []

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SENATOR LATHROP: Thank you. []

PATTY SMITH: Could I just add one more thing that might help? []

SENATOR LATHROP: Sure. []

PATTY SMITH: The gentleman that spoke--my name is Patty Smith--the gentleman that spoke about the hours and the ICAP and that, I could give you a little bit more clarification on it. There is this ICAP process that they do not implement. Jane (phonetic) is right now in her third ICAP and the last two haven't been implemented yet. So now we'll have three ICAPs that are not implement, and it's because the state has not been able to move. It's all tied up in the Bill M. case and tied up in committees. But it's been tied up for I think it's almost ten years, about nine years of tied up. And as a result of that, and maybe I'm not explaining it properly because I don't know all the state stuff. I just know what it did to us. By making the hours so few, especially when the gentleman told you about the day hours and then the night hours, what that sets up is a very difficult situation because if you only get 27, like that man said I think 26 or 7, Jane (phonetic) has like 27 or 8, you then have only got enough hours to go to a workshop or to an enclave, which means a kind of a mini workshop place where it's better than a workshop, but it's an enclave in a business let's say or maybe the dishwashing at Creighton University at their dinner there you know. And so those are the only two things you can do. And at that, one parent called me the other day and not the...his name is Joshua (phonetic), they will not accept his 29 hours because he's too difficult to serve at a workshop. So they're just stuck. They can't get him into a workshop. And the state will not...and they appealed it and lost. And so by not implementing this ICAP, and you gentlemen are going to have to figure out what this all is because if you don't, you've got one more stumbling block in trying to solve some of this. Because if they don't implement those ICAPs, like for instance, Jane's (phonetic) ICAPs clearly state that she needs more hours. I mean, it's all documented. But they won't implement them

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because they're waiting because of these problems of the...they say it's the up-and-down hours. They're trying to get people to go down in hours so they can go up on hours. I mean, I'm telling you guys if it took you nine years to figure this out, I mean, this is a long time to figure something out. And now we have...I'm on three more committees this fall that are trying to solve some of these problems. Well, it's a lot of bureaucracy. But what it does to the people and what that man said to you, you know, when he said that she had smaller amount of hours and then she's put into a place with people with more hours. What that means is that these people with the more hours have somebody who has more difficult behaviors. So you put his daughter in with the, you know...and then she is getting into a situation she doesn't need to be with. And he is not the only parent. I can tell you of parent after parent who has come to me and said, how can we get the hours balanced out better? I am very fortunate because (a) I'm still living, and that Jane (phonetic) has the apartment in my downstairs because she doesn't need...she has 62 night hours. So if she was going into an apartment, she'd be in the same problem that this gentleman was because she'd be real short on hours. And so it would be really good for you to spend a little bit of time...Mr. Severance was here in June, if you recall, talking to you about how they do these ICAPs. And I got to tell you something, I like Don Severance, I like all of these people. But if you cannot figure out how to solve a problem in eight or nine years, the state's got a problem, and it's causing people trouble, and it's causing trouble for the providers. And so I just want you to assure that because he explained it quite well. But I know the part about how the state has...because we went through these appeals as much as we have, and we have not won any appeals. I spend more money than you'd ever want to hear appealing and got nowhere. And so it causes a lot of trouble with her trying to work because they said at the beginning they said she couldn't work, like for ten hours a week they had her...that's another whole story, they had her at SSI all messed up. So you just need to know that the state has got to start implementation of ICAP, and they need to get...actually what the people are fighting over is that it isn't a good system. And I told you that the other day, Steve. It does not measure the right things. And so they need to find a way to have a proper measurement of their assessment of people. Then assess the hours and fund

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them. And this also, if you stop and think about it, has grave consequences for the providers. So I just wanted to mention that to you because the gentleman did a good job at beginning of it that I wanted to put more on the end of it because the ICAP process is not being used. It's just talked about. []

SENATOR LATHROP: Before you leave, let me just make sure I understand the ICAP process... []

PATTY SMITH: Okay. []

SENATOR LATHROP: ...and remember how it was explained. But they go through an assessment process. []

PATTY SMITH: Yes. []

SENATOR LATHROP: And that's supposed to be... []

PATTY SMITH: A paper... []

SENATOR LATHROP: ...an objective process to determine... []

PATTY SMITH: Yeah. []

SENATOR LATHROP: ...what each individual who is looking to the state for services... []

PATTY SMITH: Right. []

SENATOR LATHROP: ...what their needs are. And then they go through the ICAP process to weigh how much services a person with... []

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PATTY SMITH: Will get. []

SENATOR LATHROP: ...that level of need requires. And then they get so many hours of credit... []

PATTY SMITH: Right. []

SENATOR LATHROP: ...that you basically can spend... []

PATTY SMITH: They're units. []

SENATOR LATHROP: Units? []

PATTY SMITH: Units of service, yeah. []

SENATOR LATHROP: Units of service that you can spend in the community. []

PATTY SMITH: Right. []

SENATOR LATHROP: And what you're saying is if they go through the ICAP process...first of all, you don't think that's a perfect process and that it's flawed. []

PATTY SMITH: Right. []

SENATOR LATHROP: But even when it comes up with a certain number of hours, they're still rationing those units. []

PATTY SMITH: Yes. And because of this...this fight started before I ever came back in the year 2000. It was already roaring then. The advocates and the people in different

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positions that have been on all these committees--I wasn't on them--have told me that all of the committee said they should do it this way, and the state says they should do it this way. And that battle still goes on, and in another month they're going to have a gentleman from Minnesota come down, Charlie Lakin (phonetic), and he will be the specialist that will come in and try to help people to understand what it is they can do, could do, would do. But I think that it's important for you to know that like that gentleman is saying that he's like banging his head trying to get what his daughter needs. He appealed it, they won't change, it's insufficient, and it causes his daughter problems because she's getting into the wrong...you know, she's got the wrong...and this is probably common, this thing of getting to the right roommates and the right people. If you get the right one, it's great. For my daughter, my daughter does not want to live with anybody. She has autism. She does not want to share her living area with anybody. And to the best of our ability, we'll let her be like that. When I die, she gets my house and somebody can come live where I live. That's the kind of a service where you have a host family. I'm her host. And I want her to live in that kind of a situation because she does not want roommates. And so that's one way...there's ways you can get around some of these things. But you gentlemen need to know since you've got so many things to figure out, like what it takes...and my last thing, the state now is saying that they will adequately really try to figure out what people leaving Beatrice are going to get for hours. And I don't know what process they're going to be used. I haven't been told. But I've heard the community providers have said that within 6, or is it 12 months, they're going to cut it back to the ICAP. That is a terrible plan. I mean, if it takes this many dollars to serve them for 6 or 12 months, why would you think that this is somebody that really needs a lot of...(end of recording) []

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[]

The Developmental Disabilities Special Investigative Committee met at 9:00 a.m. on Friday, August 22, 2008, in the Carstens Social Center at the Beatrice State Developmental Center for the purpose of conducting a public hearing. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Tim Gay; Arnie Stuthman; Norm Wallman. Senators absent: Greg Adams, Abbie Cornett. []

SENATOR LATHROP: My name is Steve Lathrop and I have to begin by apologizing for being late. I guess the trip from Omaha is a little bit further than I thought it was, by about ten minutes. Thank you for coming this morning. We're here today pursuant to and to conduct a hearing as a consequence of LR283, which was prompted by problems that were present or appear to be present at the Beatrice State Development Center. The purpose today, we held hearings yesterday to listen to family and special interest groups that have a special interest in the developmentally disabled in Nebraska. We thought it important, the commission did, to come here today to hear from staff, current staff, former staff, those who have been involved in working right here at the Beatrice State Development Center, so that as the commission we get the point of view not just of the administration, not just of Health and Human Services but from the people on the front line who are here every day, day in and day out, and can give us an idea of what we're doing well at Beatrice and what we are not doing well, where the problems are and how we might come to a solution and how we might correct those. I want to begin by introducing my fellow senators and the folks that are here to help me today. I have...many of you probably know Senator Wallman. He is the State Senator from this district, has a special interest in Beatrice, and Senator Wallman serves on this commission. To my immediate left is Senator Tim Gay, who is from Papillion, serves on the Health and Human Services Committee and is, of course, involved in this issue as well. I'm also joined by Senator Harms, who is from Scottsbluff; and Senator Stuthman, who is from Platte Center. And our committee clerk today is the very able Beth Otto. So the way we will conduct our hearing today is we'll just ask you to come up. There's no

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order. We don't have a list or a batting order. It will just sort of be step up when there's an opportunity, and we'll hear what you have to say. There is no subject, when it comes to these hearings, that is off limits. There is no subject that we came down here to hear you say or we don't want to hear you say. I like to think of this as an open mike for the employees of Beatrice and the people who are involved in the care or have been involved in the care of people here at the Beatrice State Development Center, so we are very interested in what you have to say. I don't know what the level of concern is among employees about their ability to be candid with us today in what they have to say. I would like to encourage you to be candid, to be blunt. The only thing, the only thing we ask you to do is to be honest in your remarks and then be...give it to us straight. Give it to us straight. If there is some concern that there might be retaliation by the administration, I've been assured there will not be. But if you feel like you have been candid with us and you have been retaliated against, I want you to contact my office, my legislative office, directly and I will look into it. I have been assured by Mr. Wyvill that he will look into it. And we have the assurance of John Wyvill that there will not be any form of retaliation, and if you feel that there is because of the remarks or the comments that you've made, you may contact me directly and I will personally follow up on it, as will...and we'll go as far up the chain of command at Health and Human Services as is necessary. And I see Chris Peterson shaking her head in the affirmative. She agrees with that. So again, to get the full benefit out of what we came down here for today, it is important to us as a commission that you feel free to speak your mind and free to tell us the good, the bad and the ugly. So with that, just a few housekeeping things. Beth is so good; she types out what I should say and I never read it. But what I would like to do is to start out and get a sense of how many people wish to testify today. If you can just raise your...pardon me, raise your hands. Three, four, five? Are there more of you? Just a little nervous yet? You want to see how it goes? That's okay. I certainly understand that, and then there's the public speaking piece of this. You don't need to be nervous in front of this commission. We're not going to grill you or cross-examine you. We do, we'd like as many of you to come forward as you feel comfortable and as you're able to. And yesterday we had sort of the ten-minute rule, talk for ten minutes. I'll say if we have five

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or six people and that's all then we'd like to hear you tell us everything you have to say. And if you didn't raise your hand and you feel a little more comfortable and you want to come up after you've heard some other folks speak and you have something else to say, please do, because the more we hear the better informed we'll be. And one thing that I should have read off that sheet and didn't is, if you intend to testify, we need to have you fill out a form. They are on the table. It just is your name and probably your address. And the reason we do that is not so that we know who to pick on but to make sure that the record has your name so when we transcribe these proceedings, as they will necessarily be, that we get your name right and we know where you're from in case we have to get back to you on anything. So we'll only ask you to fill the form out and sit in the chair and let the mike pick them up. Yes? []

BETH OTTO: Yeah. Or they can just put it in the box right there. []

SENATOR LATHROP: No, the mike. []

BETH OTTO: Oh, it's ready to go. []

SENATOR LATHROP: Okay. Just sit down and speak naturally. If we have a problem, Beth will tell me and I'll stop you and we'll have you speak up or move the mike around. So with that, we'll begin. And if you'd like to speak, we'll just have you come, kind of move up into the front row and we'll take people out of the front row. Thank you. []

MIKE MARVIN: I don't think we have a page. []

SENATOR LATHROP: It doesn't look like we have a page. []

MIKE MARVIN: (Exhibit 1) Okay. Good morning, Chairman Lathrop, members of the committee. My name is Mike Marvin, M-i-k-e M-a-r-v-i-n. I'm appearing on behalf of the Nebraska Association of Public Employees, which is affiliated with the American

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Federation of State, County and Municipal Employees. Our organization is the labor organization that represents many of the state employees at the Beatrice State Developmental Center and the other 24-hour facilities. These all fall under your jurisdiction. Your oversight and continuing work on the quality of care for those individuals in our state facilities is greatly welcomed by our membership. For the record, when we say your jurisdiction, we mean yours and the Legislature's jurisdiction. The Nebraska Constitution clearly establishes the Nebraska Legislature as the ultimate decider with regard to the management, control, and governing of all state institutions. Article IV, Section 19 reads: "State Institutions: management, control, and government; determination by Legislature. The general management, control, and government of all state charitable, mental, reformatory, and penal institutions shall be vested as determined by the Legislature." Given this responsibility, we would urge the committee to do three things in the wake of your investigation. First: We'd like you to commit to many more years of oversight. These challenges have been present for many years and we suspect they will need a commitment from the Legislature to continue your oversight. So whether it is by statute or by legislative rules, we urge you to continue this oversight activity during the upcoming years. It was testified to at earlier hearings, BSDC used to be the model institution. Since at least 2000, when the state was under budget pressures, it has not been. Is it a coincidence that the problems started at the same time as the budget problems? I don't think so. Institutions such as BSDC, who care for our most vulnerable of our citizens, should be looked at very carefully, both by the Governor's Office and the Legislature, before suffering any budget cuts. The first duty of government is to protect its citizens, chief among them, their most vulnerable. It is our opinion that former Governor Johanns and current Governor Heineman chose not to make the tough decision that BSDC and other 24-hour facilities be exempted from budget cuts and that the Legislature was not made aware of the deteriorating conditions at BSDC. Continued oversight should eliminate that problem. Second, statutorily establish best practices staffing standards. Consistent through every third party that has investigated BSDC is the staffing or understaffing problem. Every piece of testimony our organization has provided over the last several years to standing committees of the

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Legislature has enumerated the failures of management who insist upon a minimum staffing level, which assumes a rapid replacement of staff when they are sick or on leave or, as I forgot in my written statement, or when they quit or are fired. We will provide the committee with a list of statutes passed in other states that delineate staffing standards. However, we believe that as you study this issue you will receive real life recommendations from our members that should serve as the basis for statutory standards. And again, staffing gets back to the budget. When you're confronted with budget problems and there are, say, five vacancies, it's easy to cover those five through overtime. In fact, some overtime is good. It makes some employees happy. But then as the vacancies continue, and you can say, well, my budget is a little over, I can bring it down by not filling those vacancies, pretty soon you're in a hole that you can't find your way out of, and the mandatory overtimes begin and people get tired and they quit. And then it creates more of a problem. So honestly, I believe at the heart of most of these issues down here have been budgetary at the beginning. Now it may be others in combination with the budget. So setting staffing standards, budgeting for and holding the administration to these standards is mandatory for the success of BSDC. Third, we'd like to ask you to keep track of the folks that leave our institutions. Our membership is greatly concerned with the quality of care and accountability of care that will occur as our clients are moved out of our facility into underfunded and understaffed programs in the state. We saw problems with that when we closed the Hastings Regional Center, cut back at the Norfolk Regional Center. People fell out into the system and out onto the street. Nobody knows what happened to a lot of them. And you cannot be making good decisions on how you're funding things when nobody knows what's going on. In closing, I would hope that the committee, in its findings, recognize the dedicated and professional staff who do God's work down here and they truly care about their patients. Might I also add to this, which is not in my written statement, that at times this is a very dangerous job for our staff and the people here. The unpredictability of some of the clients who have behavioral problems, you never know when it's going to happen, what's going to happen. I think...I don't know if I'm violating anything here, but there was a person from...that was on staff last night here at BSDC who was assaulted and had to

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go to the hospital, you know. So again, that also goes to staffing standards, if there's enough staff around to take care of those problems, you know. So for the last eight to ten years, many of the employees here have worked 16-hour days, 12-hour days; two, three days a week; five days in two weeks, you know. And to put that in perspective, if you guys go to work at 9:00 a.m. at the Legislature, 16 hours later is 1:00 a.m. the next morning. You know, are you going to be alert? Are you going to be awake? Is it going to be a safe environment for the staff, for the patients here when people have been working that many hours? We have this problem not only here but we have it in all of our 24-hour facilities, the vets' homes, the regional centers, at each one. In all the corrections facilities it's really starting to show up now. So we would urge you to take a strong look at what's going on. I know your focus is BSDC, but I would urge you to take a strong look and see if there's correlations to this in the other 24-hour facilities. And with that, I'd be happy to answer any questions. []

SENATOR LATHROP: Thanks, Mike. Senator Harms. []

SENATOR HARMS: Thank you, Senator Lathrop. Mike, I'm just interested in visiting with you about a couple of questions. You talked about staffing standards. []

MIKE MARVIN: Yes. []

SENATOR HARMS: What are you referring to? Are you referring to more than just the hours? []

MIKE MARVIN: Number...a ratio of staff to patients. So if there's adequate staffing on level...adequate staffing levels here and there's adequate staff so that we can cover vacations, we can cover sick, we can cover the day-to-day problems that have...without having to mandatory large number of employees into 16-hour days. We know that on a daily basis something may happen. That's why there is mandatory overtime language in the contract, because recognize that you can't do for everything

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that could happen. But that has been abused over the years where they have used that language that everything is an emergency and we're going to 16-hour days a lot of people. []

SENATOR HARMS: Okay. When you look at staffing standards, what about the qualifications of the staff? I mean, that fits into a lot of thing. I'm assuming that the qualification of staff, finding the staff (inaudible). []

MIKE MARVIN: Finding qualified staff, yeah, you should set some standards for what the qualifications for staffing is and they should receive adequate training and they should receive ongoing training in new developments or new ideas, so yeah. []

SENATOR HARMS: What about budgeting? In regard to budgeting, how much do you feel like this center is short? I mean financially, when we look at this, I've heard this discussion, you mentioned this discussion...I mean this particular question, if we look at the budget itself what do you think we're short and what do you think it's going to take to bring this center back to where it belongs? []

MIKE MARVIN: I honestly can answer that because I don't have all the facts and figures of everything, but I think where you...in the previous year we're looking at about a \$52 million budget down here, and in this last fiscal year we're down to \$48 million. My concerns are when you bring the budgets down in these areas, you know, that you look at all...what the effects of that are. I wish I could tell you how much money it would take, but that's why they pay you the big dollars and not me. (Laugh) []

SENATOR HARMS: You referred to the administration here and holding them accountable for the standards. What are your views about the administration here and the general operation of this? []

MIKE MARVIN: Well, Senator, let me qualify what my statement said there. I don't even

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mean just here. I mean at the levels above him, all the way through Chris Peterson, who's responsible for this, to the Governor who is responsible for overlooking Chris Peterson. What do I think of the staff here or the administration here? My exposure to John Wyvill, since he's come on here, very positive. John has been very open with me, very open to any suggestions that we have for him. I know that he meets regularly with our stewards out here to see what the concerns are, what he can do, you know. Is it genuine? It may be too soon to make that determination but I believe it is. I believe we're moving in the right steps. I believe that Chris Peterson has a genuine interest in getting this straightened out. I think they will be open to ideas and discussions. []

SENATOR HARMS: You refer to statutory standards. What statutory standards do you think need to be changed to make this center (inaudible)? []

MIKE MARVIN: When I'm talking about that, I'm strictly talking about, in my statement, the staffing levels to make sure that there is adequate staff to do the job that we're charged with, that we're not trying to do it with too few people. []

SENATOR HARMS: Okay. Thank you. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Mike, I just kind of want to dwell a little bit more on what Senator Harms was talking about. If you had to itemize or pick which would be the top thing that we should be addressing between the three--budget, staffing...staff training, or staffing level--which do you think would be the most important and that would affect, you know, the others the greatest? []

MIKE MARVIN: I think staffing levels would be the most important. That would also tell you what your budget numbers would do. Staff training, I think would probably be right there with the budget, you know? []

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SENATOR STUTHMAN: So in order to accomplish what we're trying to get to, the most important thing you feel would be the staffing level to start with. []

MIKE MARVIN: Right, Senator. If you say this is what our staffing levels are, this is what we have to do, that would then tell you how much money you need to budget for that staffing, you know? So...and then I have no idea, to be honest with you, what ongoing training costs if they had to bring people in to do it, if we have people within the state that are capable of doing the ongoing training and how that works. []

SENATOR STUTHMAN: Do you think staff training would be very important with the circumstances that these people are working under? []

MIKE MARVIN: Sure do. I sure do, Senator. And not only staff training but maybe, as I'm sitting here thinking about it, some kind of a mentoring system for people who are maybe having some problems with some of their issues that come up in their training and doing their daily job, somebody that they can go to and they can talk to and say, I'm having these problems and with this type, and maybe get some extra training or support. []

SENATOR STUTHMAN: Okay. Thank you, Mike. []

SENATOR LATHROP: Senator Gay. []

SENATOR GAY: Mike, thanks for coming. When you're talking about overtime, the first thing, if you watching that budget, overtime is a killer on budgets anyway. []

MIKE MARVIN: Yes, it is. []

SENATOR GAY: So...but I think...and this is more of a statement and...but I think what

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we're going to get out of this committee a little bit, we've got members from Appropriations, Health, Labor, we've got all the people and all the players here to look into this and speak amongst ourselves as we go and work on a budget this coming legislative session. So I think we're in a good position here. Timing is right for what you're saying. But I guess I'm just going to tell you, we'll make a commitment to look at the budgets and there's a balance, when you run a 24/7 facility, whether it's law enforcement or anywhere else we're looking at throughout the state, what's the optimum level staffing, overtime. But any good manager I think is going to look at overtime and say, hey, how can I get rid of it? The steps they're taking we need to keep following up on, who are we hiring, some of these processes that are already in place, we need to make sure. And what I'm doing here is asking for your help, keep on us to make sure we get some of the employees hired that we need. We're making changes. It won't happen overnight. But I think that's amongst all of us. We need to make sure we continue to go and that I talk or Senator Stuthman, that Health Committee members are talking to Appropriations Committee members, who are also talking to Labor Committee members, whatever the case may be. Because sometimes we get in our silos and we only look at one part of the puzzle, but what you're saying, I think, and I jotted down a few notes, is make sure you're looking at all these things together... []

MIKE MARVIN: Right. []

SENATOR GAY: ...and find out what the optimum balance is between staffing, overtime, and budgets. Because we can't just say ignore budget and just throw money at a situation either. So I appreciate what you're bringing here and just wanted to tell you on record, made some notes and will follow up on it. But if you have any way you want to help as well, I'd encourage you to, not just today but later, let's talk and figure this out as well. []

MIKE MARVIN: Well, I'll definitely make you that commitment, Senator Gay. (Laugh) []

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SENATOR GAY: Yeah, I know you will. []

MIKE MARVIN: Yeah, we've talked before. []

SENATOR GAY: No, I know you will. Thanks. []

SENATOR LATHROP: Mike, I want to visit with you a little bit about you sort of...you're the lead-off guy here as testifiers go and we got sort of, what John Wyvill likes to call, the 25,000-foot view of things with your testimony, but I'd like to visit with you a little bit about the findings on the DOJ report. As I read that report, it, of course, identified a number of instances of abuse and neglect, and that report also attributed those to personnel practices at BSDC. []

MIKE MARVIN: Uh-huh. []

SENATOR LATHROP: And I suspect that you've spoken to an awful lot of people, some of whom will testify today and some of whom chose not to. []

MIKE MARVIN: Yes, I have, Senator. []

SENATOR LATHROP: So you'd be familiar with the relationship between those abuses or the employment practices that are referred to in the DOJ report and the abuses. []

MIKE MARVIN: Yes, I am. []

SENATOR LATHROP: I'd like you to share your thoughts, if you would, on the relationship between the overtime hours and maybe you can tell us what the overtime situation is or your perspective. I heard this in Business and Labor when we had a mandatory overtime bill, but why don't you give us sort of the big picture view of what the requirements are if you're a BSDC employee for mandatory overtime. How many

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hours are people putting in and what are those circumstances under which they find out they're going to have to work overtime? []

MIKE MARVIN: The circumstances where they find out can vary greatly. It can be a last minute, they're getting ready to leave, and we're going to have to hold you over because somebody called in. It could be earlier in the day that they...absolutely, no, they don't have the staff, and they'll let you know. Now our contract allows for three mandatory overtimes in a pay cycle, which would basically be almost a month of 16 hours, but what's been happening, not only here but at our other 24-hour facilities, is that sometimes it's been three in a week. Sometimes it's been three in, you know, a two-week period, but then the next two-week period you're right back into it. What that does, in my opinion, I mean we're talking about people's lives here that these people are taking care of. You're wore down. You're tired. It's easy to make mistakes. Simple mistakes have big consequences sometimes here. We can't allow that to happen. And you know as well as I that if you're up 16 hours, your mind is not as sharp. If you're working that 16 hours, you're doing...whether it's taking care of medications, whether it's taking care of feeding, whether it's bathing, I mean it's very, very simple to make mistakes. And Ted Buri, one of my staff reps, is going to talk about this a little bit more. Things that have been cited by DOJ as abuse or neglect I think are simply mistakes that people have made because they are so worn down. They are there at the end of the day and this may be your second or third day of working 16-hour days, in addition to your other days 8 hours a day, that you're going to make mistakes that are not deliberate abuse, that are not deliberate neglect, but they are treated as such, and CMS wants them treated as such. JCAHO, they want them to come down. And know anyone who commits deliberate abuse or neglect of one of the patients here needs to be gone. I'm going to tell you that. You know, we're not going to tolerate that. We don't want anything. But what happens when we get into these situations where people are working these many hours, mistakes happen. Mistakes happen when you're on an eight-hour day, but mistakes happen when...really happen when you're wore down. And to be held to such high standards that you can't make a mistake and what happens to

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the employees when they do is wrong, is wrong. You can't demand this of people. You can't demand that many hours out of them that they be perfect, so... []

SENATOR LATHROP: When this matter came before the Business and Labor Committee, many of the people, probably some of whom we'll hear today, including yourself, talked about where Beatrice...that the Beatrice Development Center used to be a place in this community that people wanted to work at. It was the place where people tried to get on, where you had to wait in line for a job, and that has turned into now it's become a place where people don't want to work because of...for a variety of reasons, perhaps the pay, perhaps the type of care, and the mandatory overtime and the suspensions. And maybe you can address for me, unless there's somebody else that's going to come behind you that will and you know that, address for me...because we have staffing problems, address the situation of Beatrice State Development Center as an employee...an employer, rather, in this community and how that's changed over the years. []

MIKE MARVIN: Senator, I do know for a fact that is also part of Mr. Buri's testimony, but I will give you my opinion here very quick and Ted will touch into it more. I mean, for years this was the employer of choice in the Beatrice area--good job, good benefits, everything there, great place to work. It is now, again, the employer of last resort in many cases because people...the reputation in the community is such that, you know, it's not a pleasant place to work, you're going to be mandatory and if you refuse mandatory you're going to be disciplined, discipline is severe. You know, the reputation has gotten out in the community. This was generations of families that grandfather worked here, parent worked here, child worked here. It's not happening anymore, you know? And, as I said, Ted will, Ted will address this more in his testimony. []

SENATOR LATHROP: All right, we'll talk to Ted about that, I guess, in a little more detail. Before I let you get away and since you are a union representative, share with us the hourly rates at Beatrice Development Center or the...if it's not the employer of

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choice, where are people going instead of the Beatrice Development Center? Are the rates of pay and the benefits and the circumstances competitive with other jobs in this community? []

MIKE MARVIN: You may hear different out of me than you're going to hear out of a few other people. After the CIR decision and for the job that has the most incumbents in it here at Beatrice, we've probably got the wage where it is competitive in the area again now. We were not. We were below. You know, our developmental techs here, they were way below what the market was in the area and they've come up substantially over the last two years. Now some of the other classifications still need some addressing. But I guess I would like to say this, Senator, that while money is a motivator and money is necessary and we will take all the money we can get from you, that job satisfaction is probably more important--being happy in your job. You know, people will sacrifice money to work somewhere where they enjoy coming to work, where they want to be. You know, and I, from my own belief, that is the primary motivator for people to stay or want to come to work. This is a good place to work. We love being here. And most of our employees here absolutely love their jobs. But it's the other issues that go with the job, the mandatory overtimes, the long hours, the disciplines, the...that's...I think that's wherein our problem lies. And again, as I say, there's a problem with discipline, let me reiterate, I don't think that anybody who deliberately abuses a client here needs to be here, but we can't treat every mistake, particularly when you've been here long, like it is abuse, so... []

SENATOR LATHROP: All right. Thanks, Mike. Are there other questions? Yeah. Oh, Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. Yes, Mike, thanks for being here. You know, some institutions, like hospitals and nursing homes, go to ten-hour days. Do you think the employees are up for that or not? []

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MIKE MARVIN: Senator, very possibly. I don't know. I think some would welcome 10-hour days as I'm not working 16s, you know? But then it gets into the point then what if somebody doesn't show up for that 10? Are they "mandatoried" for another 10-hour shift and they're working 20 in a day? You know, there's a lot of issues to be resolved around something like that. So, I mean, there are things that we are open to discussion on with management. []

SENATOR WALLMAN: Thank you. []

SENATOR HARMS: Can I say one question? []

SENATOR LATHROP: Yeah, Senator Harms. []

SENATOR HARMS: Mike, I would just like to follow up. I don't believe that all the issues here are tied to overtime. []

MIKE MARVIN: No, they're not. []

SENATOR HARMS: And my views here, as just reading what the DOJ report is, I think there are bad choices in hiring the wrong people. Secondly, I believe that we don't have a system here in place that really manages this operation appropriately. I believe very strongly that when you hire someone and they plug in their time card and they go watch a ball game or they leave campus, there's something wrong with this institution. []

MIKE MARVIN: True. []

SENATOR HARMS: I also think that when you look at this and look at the communication link here, there is very little communication, according to the DOJ report, and that people aren't communicating. There aren't reports that are being filed appropriately. It looks like to me, as I view this, I might be wrong but be anxious to hear

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what the staff says here, that it's disjointed completely and that, in fact, we don't have appropriate management here to make this correction. Putting money into here and hiring people will make no difference unless the culture of this organization changes, and that management style will have to change with that to make this appropriate so that the people we have here will receive the appropriate care. We are responsible for these folks. And so I don't want everyone to think that it's just because of overtime. I think it does have an impact, but there's so much more beyond overtime pay and overtime issues here that need to be resolved. []

MIKE MARVIN: I agree, Senator, you know, and I think that part of the problem with hiring the right people is that the right people don't want to come here anymore because of the bad reputation, and a lot of it is what you stated. You can't get the right people to come in. They hire who they can. []

SENATOR LATHROP: All right. Thanks, Mike. []

MIKE MARVIN: Thank you. []

SENATOR LATHROP: I appreciate your testimony today. And next up, all right, we have somebody. We have a volunteer. That's good. I should have said this and if you'll let me interrupt you for just a second, when you come up, if you can sit down, make yourself comfortable, and then tell us your name and spell your last name for us. []

JONATHAN POTTER: (Exhibit 2) My name is Jonathan Potter, like Harry Potter, P-o-t-t-e-r. I work for 406 State as DT staff and I'd like to share some issues with you today. Excuse me. I'm not a very good public speaker. I'm much better at written communication. Okay. Dear members of the committee, when you look around campus, it appears beautiful, well-kept, an even serene. It's a lot like my first wife; it's not until you break the surface, until you get off on your own that you start to see what it's really like. I'm not sure that the tours you have taken...I am sure that the tours you have taken

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here have lived up to all the dog and pony show standards your tour guides had to offer--nods, smiles, pats on the backs all around. I have previously discussed the breakdowns in communication in a letter regarding a town hall meeting I was unable to attend on Tuesday, April 15, 2008. I have since found two errors in this letter and have included that letter in here. I'll give this to you and attach the corrections. This letter went to Mr. Wyvill and Mr. Stegemann, who hosted the meeting. It also went to...I e-mailed it to Senator Wallman and it traveled quickly amongst the DT staff on campus. One of the things it spoke of is gravity in communication: What goes up must come down. There has not been any response to that letter or the concerns addressed in the following town hall meetings. Gravity in communication is a problem at BSDC. What I'd like to speak on today is caring for the caregiver. It is possibly the most important job on campus that is not done well. By no means is this an easy job, as it encompasses a large variety of problems and issues that affect the everyday professional lives of our DT staff. Further, the duties of this are multidisciplinary duties belonging to various professionals and administrators across campus. These issues include, but they are not limited to: communication; safety; suspensions and overtime; rights, responsibilities and consequences; administration and professional support; and advocacy. As I have previously mentioned, I have covered major problems in communication in a previous letter and will let that letter speak for itself. As well, I covered safety. I would like to touch on that topic a bit more as an update and as further issues that have come up. As far as DT staff has been made aware, there are still no current plans being made to protect staff from individuals who have a habit of spitting during target deceleration behaviors. Further, I would like to add vaginal secretions to this, as it ties to protective gear. While she did it at her previous BSDC unit and she has not done it since coming to our unit, we have an individual that will smear vaginal secretions on staff during target behavior decelerations. In one case, she even stuck her hand covered in vaginal secretions in the mouth of staff. Having spent quite a bit of time on that unit, I remember that they were instructed to don body suits. Once again, as was the case with spit socks, the answer was to stop protecting the individual from harm so that everyone can run, obtain, and don bodysuits. Failure to protect from harm is abuse and neglect. Not

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only do we need realistic answers and solutions, we need someone to care enough about staff's safety to find them and get them implemented. I covered spitting well in the other letter, so we'll leave it here. I'd like to...I have a Case A. We have supervision cards to help remind us and unfamiliar staff what exactly the levels of supervision of individuals are that need extra tending to during various circumstances. Many of the ladies' cards require two staff in the area during a physically aggressive or self-injurious target deceleration behavior, and a few also include while agitated due to the history of quickly switching to the target deceleration behaviors. On May 27, 2008, the facility was once again short on DT staff. I was moved to another unit, leaving three DT staff on the unit. Our housekeeper, a former DT staff authorized to help, agreed to help while one of our staff went to the rest room. During this time, one of the individuals became agitated when verbally redirected for making a face at a peer. She then shut the dishwasher on a peer that was about to use it. Upon this redirection, she realized that she lost her reinforcement. She grabbed a sink faucet, bending it down and then up, breaking it and causing water to spray everywhere. She continued to yell at staff as she was asked to clean up the mess. When back in her room with the DTIII and the housekeeper, requiring two because of agitation and property destruction, she went to her bathroom, took off and broke her glasses. She then attacked the two staff, busting the DTIII's lip and ripping off her glasses. She also busted the housekeeper's nose, causing it to swell and bruise, and her glasses have to be repaired. We now have one staff pulled to another unit, two staff with the individual, one staff with a one-on-one supervised individual, and the rest of the individuals are now technically unsupervised, leaving us out of compliance with our supervision cards as well as our BSPs. I was on break and came in and found the DTIII icing down her lip and sitting with the one-on-one, as well as the rest of the individuals, while the other two staff were back with the agitated individual. I don't remember exactly what the housekeeper was doing, but I believe she was tending to her injuries. The DTIII called the timekeepers to get me back as the individual had not calmed as of yet. It took them one hour and 15 minutes to get me back. This is absurd! It's unacceptable. It's in violation of our BSPs supervision requirements and adds to the perception that our safety and that of our individuals is not

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taken seriously. An individual takes out two staff, okay, as long as no individuals were hurt. We've had been a mandatory/advised four staff, but upon our most docile and nonviolent individual earning community placement, it was decided to move us to a mandatory three staff. This was based purely on numbers of individuals versus staff and not on the facts. Having been getting nowhere with yet another manager we were about to lose, I wrote a note to the area administrator. This finally ended when the temporary manager said I would get nowhere going the route I was going. This basically meant I would get nowhere going up the chain of command; I would have to go to the team. That was comforting, considering we had already been losing that battle there, too, and the manager we were about to lose was to become our QMRP. I have included some of the correspondence regarding this incident. We already knew where she stood and it played out as expected. We have continued to beat our chests, but we might as well be the town criers in a ghost town. Second case: On Monday, August 11, 2008, one of our individuals had a trip with our DTIII, our QMRP, and a DT staff that agreed to come in on her day off. This trip was for the individual to take her boyfriend from another unit to Lincoln to meet her dad and have lunch together. This gives us four staff--one staff in Lincoln and three at BSDC. The three staff, one is with the one-on-one individual, covering for the birthday girl at Treasures Unlimited, and two staff with the other three girls. One of these girls went to her job at the snack shack. What this looks like is that we have two staff on two individuals. We received a phone call that I was being moved to another unit because they only had two staff and their HSTS, while we had four. They were counting a staff that was in Lincoln, unable to help if something were to happen. Normally, this would not make us happy but we'd deal, but unfortunately it hadn't been normal. One of the two individuals, a schizophrenic, had been having serious issues due to staff being suspended, on vacation and, to her, just plain unreliable. This is a serious issue for her and for the last week and a half she had been having serious issues. We even had a psych clinic scheduled for her that had not yet taken place. The other individual had been known to switch gears just by redirection and by agitation of her peers. You heard about here in Case A. I fought but, in the end, lost. I was visibly upset when I went and spoke with my manager. I was told there was nothing he could

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do. Further, he asked where our HSTS was. I didn't know. He then told me he would put on a radio, as he'd be across campus, and he would get our HSTS to go with her. Not happy but mollified, I went to the next unit. I get to the next unit and their HSTS, who shares an office with ours, informs me that our HSTS is on vacation this day. No one was sent there to help her. Upon finding the HSTS on vacation, our manager didn't help. Further, even knowing his staff was stressed, he was not willing to help cover lunch breaks. She had to go to our former manager who is in charge of the developmental specialists. She basically had to get mad to show how stressed she was and needed a break. Further, she was told to handle the routine by herself and get it done. They had to pull me off a unit that did not have available or willing professional support to put me on one that did have it. Fortunately, this time there were no serious target deceleration behaviors. Suspensions: For some individuals, suspensions and allegations protect them from harm, doing the job it was meant to do. However, there are a few units on campus who have individuals for whom suspensions and allegations are a tool, a toy, and even a weapon, all more powerful than anything they could do physically to staff. They know the system and it's like a finely honed sword. On 406 we have a couple of individuals that know exactly what to say. We have one individual we cannot redirect without her running to the phone. Just recently, she called the CEO again and laid a false allegation on me and a coworker, saying we called her a retard and said she'd be there the rest of her life; one of us didn't say one thing and another say the other, we both said exactly the same thing. Neither of us had said that. However, we get pulled in the office and told we're suspended. They check with the investigators and we had to talk to them before we leave campus. While there, the investigators asked us about this individual's false allegation policy. This is a historical problem for her and is the same individual I discussed in the previous letter. When I told them she doesn't have one, they were shocked. Deb Turman had more or less the same reaction when I told her of the lack of policy for this individual. I talked to her prior to my suspension. They took her statements and we hit the bar. What else was there to do? Seriously, we heard nothing until we got the notorious suspension nasty-gram from our manager about halfway through our suspension when we...though we didn't know it at the time. Then we hard

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nothing again until they brought us back. I had a couple of conversations with a union rep, but he didn't seem to know any more than I did. The next thing I heard was, on Wednesday, July 30, Pam Spier asking me to come back. My days off are Thursday, Friday, so she set up a meeting on Saturday morning before going back to my unit. She gave me a tutorial or counseling on the rights of individuals and what to and not to do. I was told that because there are so many suspensions, they know there are abuses going on. I had heard rumors of splitting up 406 staff and asked her about it. She said there was talk. I let her know that I was not threatening, but if that were to happen I will leave BSDC and head to LRC. It's actually close to home. Having not done what I was accused of, my allegation of abuse was not substantiated. When I got back to the unit, I was informed that our other DTIII had been suspended the day or two before by our individual that actually has a false allegation protocol. When she came back, she told me in her interview with our manager he had said he knew there was abuse going on. She said that he told her he could only find a couple suspensions in her file and knew there were more. If there was one more suspension on the unit, they'd split us up. According to contract, those suspensions should not have been in there since there was no discipline and they were unsubstantiated. I would like to note that none of it was said in a threatening manner. Many things happen to you when you get suspended. You go home wondering if you'll have a job or an abuse charge added to your public record. Even being innocent, I was a little more overwhelmed than I would have thought I'd be. You are treated guilty until proven innocent. I was fortunate enough to have her do it on the first day of the pay period and was back before it was over. If you get hit on the second Monday or Tuesday of the pay period, you are going to lose six days worth of pay off of your check, regardless of your innocence. This I object to. Bills have due dates and do not care if you will get your pay back eventually. It's bad enough dealing with a false allegation, but to take money away from taking care of my child is too much. Further, in the last year our unit has lost literally thousands of dollars in lost overtime, and that's just our unit. The other units have experienced the same. Personally, I lost three scheduled shifts of overtime. That's a gross loss of \$437.97. That is money robbed from taking care of my child. It's just too much. Add insult to injury, the three

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overtime shifts I lost put me under the three-shift limit to be mandatorily held over for the next shift. On Sunday, August 17, I was told because I didn't have my three shifts in I would have to stay into the second shift. Further, we had two other staff who were told when they came back, one of whom lost her four scheduled overtimes putting her under the limit, they were both mandatorily held back their first day back to a problem unit where there was no regular staff. Let me make this clear. I am innocent. I lost money. I was brought back unsubstantiated, and they tried to mandatorily hold me over, still be punished for something I just did not do. List of consequences for the individual who lied--none. All consequences are transferred to staff and her peers. I'd like to...Rights, Responsibilities, Consequences: It is well-known that rights come with responsibilities. Our team has come a long way in trying to promote and teach our individuals how this works. We need to take it a step further. Rights come with responsibilities whose use has consequences. In the politically correct work up, consequences has almost become a dirty word, erroneously synonymous with punishment. In our effort to make sure our individuals are not being punished, we have gone above and beyond the call of duty in removing consequences from their actions. If the individual trips, we had better not let them fall. If they fall, they better not get scratched. If they get scratched, they better not hurt. Sometimes it feels as we are spending most of our time throwing ourselves under them, making sure they don't get hurt. Unfortunately, by removing these natural consequences, they are also not learning to walk on their own. For example, for a public rights, responsibilities and consequences, I have the right to drive a car. I have a responsibility not to drive drunk. The consequence of impairment is that I get fined, jailed, and lose the right to drive. Unfortunately, you can't completely remove a consequence. You can remove a consequence from one individual, but somebody else is going to pay the price. Transference of these: right, I have the right to drive a car responsibly; I have the responsibility to drive drunk (sic); consequence of impairment, I get in an accident and kill the people in the other car. That's transference. Obviously, this example does not exactly happen here; however, it shows exactly how this happens. Let's look at this from a standpoint more familiar to BSDC. I have the right to be free of abuse. I have the responsibility not to make false allegations. Consequence

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to false allegor--none. Transference of consequences: staff suspended as previously described; staff at work, working with unfamiliar staff, shouldering more of the burden of responsibility; stress is a result of the aforementioned; stresses with dealing with the allegor's peers' consequences. Their peers' consequences: dealing with the chaos that comes with unfamiliar staff; dealing with peers manipulations of unfamiliar staff; seeing accusing peer repeatedly get away with it; picking up these habits from this peer; routine disrupted, which can be devastating in the treatment of some which can last for weeks after the staff have returned; not all individuals understand what is happening; distrust of returning staff because they weren't here where they were supposed to be; you want to know, ask the individuals, they'll tell you what their consequences are. If you want to get down to the nuts and bolts of false allegations, it's bad on staff. But for the individuals left behind it is rough. They've continually described how bad it is for them. More recently, a schizophrenic individual described in the second case lost touch as a result of multiple suspensions of staff. For her, it is a betrayal that you weren't here where you were supposed to be. When you return, she won't talk to you and can be nonredirectable by your for a period of time, a day, a week, often more. We've had to adjust her meds at least as a partial result of this last episode. She has not had her meds adjusted in years. I understand we can't promote applying a false label to true allegations, but does she really have the right to put her peers through what we would call abuse if a staff had done it? Administrative and Professional Support: It is widely felt amongst DT staff that it is an us-against-them game. I covered this in the previous letter I wrote. To my knowledge, nothing has ever been done with this letter and no answer was directly given or even filtered down. Gravity is not supported in communication here. In the August 2008 edition of the "Connections" newsletter, there is an article by Jeanne Atkinson, I don't know how to pronounce her name, entitled "Department of Justice applauds efforts at BSDC." In the settlement, DHS agreed to develop a zero-tolerance policy for abuse and ensuring adequate staffing. It went on to say, keep residents free from unreasonable restraint. These two go hand in hand. Recently, 408 State has seen an increase in the mandatory minimum staffing that they must have to do their daily job. They originally went from three to four, and then on to the current five

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staff. Having adequate staffing, they have been able to reduce the restraint usage even amongst some of the most notorious individuals. Better staffing allows you to switch off if it becomes too much to handle. Even staff can get frustrated or too stressed out to continue without creating an atmosphere suitable to abuse and suitable to further aggravating the situation resulting in unnecessary restraint usage. This is why our BSPs state that we should switch out as necessary to avoid this. When you have adequate numbers, this is feasible. As mentioned in Case B, she was left without support. She was already stressed out and did not have her coworkers, manager, or professional staff to turn to, to take a break. She had to go outside the team to get that. When you have a total of three staff, you have two of them dealing with an individual's deceleration behavior; you have one dealing with the one-on-one. When those two need to switch out, do we really have the staff to do it? During the last town hall meeting I attended, the administration continued its stance on taking no responsibility and blaming others. It was DT staff's fault we were getting froze for calling in sick. For those of us who show up for work and do what we're supposed to, it was a slap in the face. We were asking for help and you were blaming us. It is not our job to discipline our coworkers or make them feel bad for calling in. That's the manager's job. If the manager isn't doing it, it's the area administrator's job. If the area administrator isn't doing it then it's the CEO's job. I learned in the Army that if your troops mess up it's your fault--take responsibility. It was brought up about an agency temp displacing staff when the unit didn't need it. He said it was the manager's fault. I asked him, since weekends and holidays are getting regularly mandatorily frozen, what was his plan for professional and administrative support. His response: "I can't work the units." First, not quite what I meant. Second, if he's not aware of how a unit should be run then how can he lead us in the right direction? Even the great generals had to get down into the trenches to be able to see how the battle was progressing. Other than the dog and pony shows, the only time I have seen him on our...the only time I've seen him or our area administrator on the unit observing things is during shift change when we have a plethora of staff, individuals' breaks, and other things going on. I have not seen them during a behavioral crisis. I have not seen them when we were short on staff. I have not seen them observe the

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individuals' employment or classroom work. At that point in the meeting, when he said that, I realized that gravity had failed and it would always be someone else's fault or problem or not matter because he couldn't work the units. So I walked out. When CMS is camping on campus, we have professional and administrative support coming out our ears. We cannot turn around on first or second shift without bumping into one or the other on the unit, in the classroom, or in the work area to help out. As soon as CMS leaves, so too does the professional and administrative support. In fact, towards the end of the last visit, though it was still called professional support, it was actually professional audit. I could see it being justified as professional support if the results had been shared with the DT staff to improve the home. On paper, it looks good. However, it really made no difference. The results of the few audits that have taken place recently have suffered the same fate. They do not share the results with us. Lastly, I would like to talk a little bit about advocacy. One of the great things about a large institution like this is that the individuals meet and literally have hundreds of advocates across campus, from maintenance all the way to the CEO. Everyone is an advocate. When it concerns the contract, the union does a well enough job to represent our interests. When it comes to noncontract issues, the number of advocates for DT staff is zero. The CEO tells the area administrator, who tells our manager how it will be. The manager is out as an advocate. The QMRP is the individual's manager. There is not one person whose sole job it is to take care of the caregiver. When staff are tired, harried, frustrated, stressed, disgruntled, and the list goes on, it reduces their ability to give the best care that can be given. You would think that being the group employees that spend the most time with the individuals in all areas of daily care and routine, that as a facility we would have someone or some people whose job it is to make sure the caregivers were taken care of and ensure gravity in communications with the caregivers in order to ensure the best possible care for our individuals. Thank you. []

SENATOR LATHROP: Thank you, Mr. Potter. If you'll...have some questions for you.
Senator Stuthman. []

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SENATOR STUTHMAN: Thank you, Senator Lathrop. Jonathan, first of all, thank you for your testimony. A question that I have is, is there any discipline for patients that are here, you know, at this facility, like you mentioned the spitting and stuff like that? Is there anything that disciplines... []

JONATHAN POTTER: No, sir. Punishment is abuse and neglect. []

SENATOR STUTHMAN: ...disciplines those people? []

JONATHAN POTTER: No, sir, punishment is abuse and neglect. []

SENATOR STUTHMAN: Punishment is abuse and neglect. []

JONATHAN POTTER: Yes, sir. []

SENATOR STUTHMAN: So the workers here must put up with anything and everything. []

JONATHAN POTTER: Pretty much. (Laugh) []

SENATOR STUTHMAN: So I mean that's...what's what...and what is HSTS? []

JONATHAN POTTER: Um, God, it's been called so many things, PSAs. It's basically the trainers. I guess that would be teachers kind of, well, kind of. They develop the programs. They develop, oh, programs for a number of things, anywhere from medication to daily care to math, you know, mathematics, to job training, whatever. They are really on the training side of it. []

SENATOR STUTHMAN: Okay. Thank you. []

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SENATOR LATHROP: Senator Wallman. []

SENATOR WALLMAN: Thank you, Jonathan, for testifying. Thank God for front-line workers. Now is there some of these clients you speak about, or residents, is there any, you know, as you probably say, they lie and there's no repercussions and they're still paid attention to, right? []

JONATHAN POTTER: Every time. []

SENATOR WALLMAN: And I can see why you have trouble getting workers. []

JONATHAN POTTER: Well, and not only that. When you start having individuals like that and they do the repeated thing, now they want to get rid of the...they want to split up the staff. So what's going to happen when they bring in the next group of staff and they start, you know, enforcing their programs and BSPs? The clients get upset. They're going to dislike it and they're going to start turning them in. You'll be all over again...you'll be back to the same thing. []

SENATOR WALLMAN: And the suspensions, even though you're innocent, you don't get paid that time your off, or do you? []

JONATHAN POTTER: If...once you're cleared, you get paid it back. But, like I said, if you're suspended towards the end of the pay period, they hold it from you regardless of your innocence. []

SENATOR WALLMAN: Thank you for testifying. []

SENATOR LATHROP: Senator Gay. []

SENATOR GAY: Thank you. Jonathan, are you still employed here? Do you still work

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here? []

JONATHAN POTTER: Yes, sir,... []

SENATOR GAY: Okay. []

JONATHAN POTTER: ...406 State. []

SENATOR GAY: Okay. Thank you. Well, thank you for your testimony. Some of the questions Senator Stuthman said about HTS, but some of these acronyms, what is a QMRP? []

JONATHAN POTTER: Sorry. Qualified mental retardation professional. It's, like I said, basically they are a manager. []

SENATOR GAY: Okay. What about a DTIII then? []

JONATHAN POTTER: DTIII, well, direct-care staffer, however, your DTIIIs, which are the low, you know, your general staff, and then kind of like lead staff are our DTIIIs, and then it goes managers. []

SENATOR GAY: Okay. All right. And then I guess listening to your stories, that's amazing what you have to go through. But I guess what I was saying, when you're looking at staff meetings, do you have like collaborative meetings where you hash out these problems? I mean, you saying, well, I go to leadership, nothing is getting is done. But do you have performance meetings where you sit around and say, hey, how can we improve this or that? I know this is a very regulatory environment, sounds like too much. []

JONATHAN POTTER: Yes and no. []

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SENATOR GAY: But what's going on, in your view of the world? Just... []

JONATHAN POTTER: We have team meetings and I've continually brought this up, but the problem we run into in team meetings is it's usually on an individual, just one. And in that meeting with that individual, you're not supposed to mention the other individuals. So really, when you're dealing with people with borderline personality disorders and other social issues, you're not helping them at all because you're not dealing with their interactions with their peers and coworkers and blah-blah-blah. And I mentioned this to the team on several occasions, is that we need to have a general team meeting about the living unit as a whole to discuss the direction that we're going and where we need to go, and it has yet to be done. []

SENATOR GAY: Okay. Okay. And then you said about sometimes you don't mind it. What's your view of overtime? I mean you said in your testimony you asked for it a few times, but what's your view of overtime? []

JONATHAN POTTER: Well, I do my overtime and I put in my overtime so I can choose the time when I...so that I don't get frozen, basically, during a time where I have family stuff or whatever going on. So I make sure that every pay period, or I try to make sure that every pay period I get my...at least my three in so...what they do is, he kind of described it earlier, is that you take two two-week pay periods. You take the one you're currently in, which is a partial pay period, and you take the last one. If you don't do...if you have your three on this one and you don't do anything on this one, right, when it switches over come that Monday you've already...you've got none in; you're up for being frozen. It just automatically drops off no matter when within that four-week period it happened. So, yeah, you just...especially if you're low senior like myself, you just make sure you get it in. []

SENATOR GAY: Okay. All right. And I guess another thing you had talked about, this is

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just my view of what's happening, is you go and there's no real coordination of events going on here. Regulations and policies, they're all to protect...none to protect you, is what you're saying. Do you think...what's your view of the regulations and policies that are going on here? Are they being enforced? Are they worthwhile or is it...I mean... []

JONATHAN POTTER: Well, you can...(inaudible)... []

SENATOR GAY: We have to have some. []

JONATHAN POTTER: As far as you have to have some regulations and I understand that they have to separate us and get us out of there because if it is a true case then, yes, you know, you got to have them out of there. So even for a false allegation, it just has to happen. But what doesn't have to happen is that you don't have to hold their pay for it because, like I said, they're not guilty yet and they may not be guilty at all. So you're punishing them for something they haven't done. []

SENATOR GAY: Okay. And you're talking about specific case there, but what I'm saying is, in your view, as you're working, trying to provide good service day in and day out, I think if you're here, you're here for a reason, because I think it takes a special calling to work in the place here. But I guess what I'm saying, is there so much regulation and things going on that we're forgetting the...why we're here? I mean it just seems to me there's a rule on this, regulation on that. I know we have to have that, but if we're not having team meetings to improve performance or do whatever, what's...do you feel that employees come in and they say, well, here's how I can improve this place, and they're just not being heard or...? []

JONATHAN POTTER: Well, that's how a lot of DT staff feel. That pretty much sums it up. (Laugh) []

SENATOR GAY: And I guess is that because we've created those regulations ourself or

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the federal government making us do these or have we ever reviewed those, in your mind? And like I say, if you don't have team meetings... []

JONATHAN POTTER: I think...I think it's a combination of a lot of things, those points that you've just mentioned, and of course it's felt by a lot of DT staff that since, you know, the professionals on up, they all have degrees and, well, we don't. It's kind of, like I said, it's kind of viewed as an us-versus-them thing. It's that we don't feel that we're all...we don't always feel we're taken serious because we're not professional. We have...one of my DTIII's has been here 20 years. She may not have a degree but I would call that professional. []

SENATOR GAY: Yeah, real-world experience. So team building is not happening. []

JONATHAN POTTER: Not really. We're lucky enough on 406 to have a very cohesive DT staff. []

SENATOR GAY: And 406 is what? []

JONATHAN POTTER: 406 State. We have five female individuals from their late...mid to late twenties all the way up to late forties. []

SENATOR GAY: Okay. And then I don't want to go on too much. This is the last question. But do you...how often do you switch your position or your job that you're dealing with, your unit or whatever? Are you being asked to do too many things or you...how often do you switch around what you do here? []

JONATHAN POTTER: When you're the extra staff and you're least senior, you can pretty much see...you can pretty much be moved every day. I mean it doesn't always happen, but there are time periods. When I was on...the first unit I worked on, 408 State, I was the extra staff and I had no seniority and I would go pay periods without

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ever seeing my unit. And yet...and then, of course, someone would get sick or go on vacation and I'd show up and I'm supposedly regular staff and I ain't been there in a month, and prior to that it might have been two weeks, and prior to that...you know what I mean? []

SENATOR GAY: Uh-huh. Yeah. []

JONATHAN POTTER: So it happens. []

SENATOR GAY: All right. Thank you. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: Thank you, Senator Lathrop. Jonathan, thank you very much for your testimony. I always respect people who come in and tell us how you feel, and I really appreciate that. I know it takes a lot of courage to do that. Jonathan, I have just one question I want to ask you. If you had all the power in the world, how would you fix this? I mean if you had the authority, what would you do to correct this? It's a tough question. []

JONATHAN POTTER: Communication, I really honestly believe communication is the key. I mean even with communication not everything can be solved satisfactorily. I mean that's just the way of the world. But at least if you know...when it comes back down saying, hey, we looked at it and this is what we're doing and this is why, at least you know why and you feel better and, you know, you can...maybe next time something comes up you know you can get it better worked out. []

SENATOR HARMS: Thank you. []

SENATOR LATHROP: I wanted to ask a few questions just to kind of follow up and I,

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like Senator Harms, I'm interested in your testimony regarding communications. And maybe it would help me to understand your situation if I understood how many people are above you. You're a direct-care person. Is that right? []

JONATHAN POTTER: Yeah, as far as... []

SENATOR LATHROP: When we talk about direct-care staff, that would include you. []

JONATHAN POTTER: Right, that's the...that would include me, correct, bottom tier. []

SENATOR LATHROP: How long have you been here? []

JONATHAN POTTER: I've been here just over three years. []

SENATOR LATHROP: And you say you're not...that at three years you're not a senior person here? []

JONATHAN POTTER: Oh no. I still have some to learn, quite a bit to learn. []

SENATOR LATHROP: I didn't know if that was a seniority thing or how much you know. []

JONATHAN POTTER: No, it's not a how much you know thing. I mean there's always...seniority thing is more of a contract issue. But I mean even...I mean even that way, we've been here three years, you still have a lot to learn. []

SENATOR LATHROP: All right. Are there people that work below you or is it the direct-care staff and you're it. []

JONATHAN POTTER: No, as far as taking care of the individuals, that's the bottom line.

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[]

SENATOR LATHROP: Maybe I can put that differently. You don't supervise anybody as a DT. So can you go up to...from where you're at to the CEO of the institution? []

JONATHAN POTTER: No. []

SENATOR LATHROP: Tell us what the levels of management are. []

JONATHAN POTTER: DTIII is, as far as I know, as far as I'm aware, DTIII is high as direct-care staff can go because they do not...unless, of course, they have a degree. []

SENATOR LATHROP: No, what I'm looking at is who is your boss? []

JONATHAN POTTER: Oh, who's my boss? Well,... []

SENATOR LATHROP: What's that person? I don't need the individual's name, but what's that position? []

JONATHAN POTTER: Well, the first line would be your DTIIIs. They can...they basically handle the general direction of taking care of the individuals on a daily basis. And then after them it would be the manager. And after him, it would be the assistant area administrator. And I'm not sure but I think it's the CEO after that. []

SENATOR LATHROP: So that would be the level if we were looking at the corporate structure. []

JONATHAN POTTER: Uh-huh. []

SENATOR LATHROP: And if you have a complaint or a concern about your working

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conditions or a patient or a resident, rather, you express that to your manager? []

JONATHAN POTTER: Correct. []

SENATOR LATHROP: And what you're telling us today is when you say something to the manager about some problem you're having with a resident or a coworker or your work environment, you make that complaint and you don't get any sense that anybody hears it or any action is taken on it. []

JONATHAN POTTER: I talked about in my speech, that trying to fight that one issue of, where was it, oh, when we had...when I got pulled in it took them an hour and 15 minutes to get me back, about getting our mandatory minimums raised. I have included a series of e-mails that I...the series of the e-mails that I went through talking about that incident, going all...going through my manager and the area administrator. []

SENATOR LATHROP: So your series of e-mails that you're referring to is your efforts to resolve an issue,... []

JONATHAN POTTER: Correct. []

SENATOR LATHROP: ...and it shows the futility of that effort? []

JONATHAN POTTER: Correct. It just didn't go anywhere. []

SENATOR LATHROP: So as a front-line person, and we heard Mike Marvin talk about job satisfaction, that would be a difficulty, or an impediment to job satisfaction would be the fact that when you talk to or make a complaint... []

JONATHAN POTTER: Uh-huh. []

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SENATOR LATHROP: ...to the manager nothing happens or there's no response that comes from on top back down. []

JONATHAN POTTER: Yes. And as I said before, that has...well, frustration and, you know, that kind of stuff has an indirect...affects...indirectly affects the individuals at well. Because if you're not at your top, if you're not on the top of your game, well, you're just...it affects their care. []

SENATOR LATHROP: All right. you also talked about overtime and I want to try to understand that, because you used some terms that I think are terms of art of commonly understood terms like "frozen" and things like that. []

JONATHAN POTTER: Correct. []

SENATOR LATHROP: But let me see if I understand it. When you get to a pay period, you have to work three overtime shifts in a pay period. Is that the case? []

JONATHAN POTTER: You're not required to, but if you want to avoid being frozen or mandatorily held over, yes. []

SENATOR LATHROP: Is "frozen" and "mandatorily held over" the same? []

JONATHAN POTTER: Correct. []

SENATOR LATHROP: So what you'll do is essentially volunteer for three shifts that are convenient for you so that someone won't tell you ten minutes before you're supposed to leave work that you have to spend the night. []

JONATHAN POTTER: Correct. []

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SENATOR LATHROP: Okay. And you have to do that, three shifts kind of immunizes you from being mandatorily required to stay. []

JONATHAN POTTER: Uh-huh, correct, and to stay immunized you pretty much need to do that pay period by pay period, three shifts per. []

SENATOR LATHROP: All right. And then the other concern you have that affects your job satisfaction or your observation of the position of a DTIII person is that the residents, who either make false allegations or spit on you or assault you, those...there's no consequence for them, and all the consequences in relationship to what goes on here fall on the staff. []

JONATHAN POTTER: Uh-huh, correct, transference, yes. And the other problem...then the other concern with that is what are we teaching them? If there's no consequences, what are we teaching them? []

SENATOR LATHROP: That's kind of a fair summary of the concerns you've expressed today? Any other questions from anybody. I don't see any. Thanks for coming down. I do appreciate your testimony too. []

PAM MEYERS: Hi. My name is Pam Meyers and I used to work on 303 Sheridan, was my main living unit, and I did work on 305 and some other places on campus. []

SENATOR LATHROP: Pam, we're going to have you talk just a little louder because I'm having trouble hearing you and I suspect that other people are too. []

PAM MEYERS: Okay. What I wanted to talk to you about today is when I worked in my living unit there was a lot of not...staff not checking and changing on second shift when you'd work overtime. They only time that they would change, check and change their individual would be when they were bathed. So they'd go from the time I worked on first

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shift, about 1:30-2:00, until 7:00 or 8:00 or whenever they felt they needed changed before they'd put them to bed. Then coming in at 6:30 in the morning, our third shifter briefs would be dry, but when you'd check the pads that the individuals were laying on, the pad would be wet, and underneath the pink pads would be soaked, so...or a brown ring around it where they were laying in dry urine. It has been reported to the manager at the time and she just didn't do anything about it. When I came back from my suspension, I was suspended for five weeks because of...well, it's a long story but I'll get into all of it later, but when I came back, I had asked a pulled staff if they checked and changed after breakfast and did oral cares, and she said, no, we don't do that until noon, 1:00. I'm like, really? So I called the new manager at that time and had him come down and I talked with him and the staffs that had told me this, and still nothing was done. I guess my point on this issue is you can report, report, report to a manager and you don't get anywhere. You can bypass your manager and go to either your area administrator or try to go through HR up in A Building and still nothing is done. A perfect example of this is lost paperwork. I had come back from a trip with another staff on second shift and asked them if they had checked and changed anybody since first shift had left, and they said they didn't have time. So I had called the second shift manager. We, with another staff, took everybody away from the supper table that night, checked and changed all 13 individuals. I had written up the paper, given it to second shift manager. She gave it back to me to give to third shift manager, which is a sister to the manager that was on our living unit, and nothing ever happened. So you write somebody up for abuse and neglect, and it doesn't go anywhere. But my suspension was for abuse and neglect and I was suspended for five weeks. It doesn't make any sense. So...which, in turn, I'll get back to my suspension, but... []

SENATOR LATHROP: Can I interrupt you for just a second? []

PAM MEYERS: Sure. []

SENATOR LATHROP: A check and a change, is that where you check to make sure

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that the resident is dry, that they don't have...they haven't... []

PAM MEYERS: Uh-huh, they're not sitting in urine or... []

SENATOR LATHROP: Okay. []

PAM MEYERS: ...feces or... []

SENATOR LATHROP: And is there a time that you're supposed to do that, every hour or every 15 minutes or...? []

PAM MEYERS: Every two hours. []

SENATOR LATHROP: Every two hours. And what you're describing is that wasn't being done regularly. []

PAM MEYERS: That doesn't happen. []

SENATOR LATHROP: Okay. Thank you. And I didn't mean to interrupt you but... []

PAM MEYERS: I mean it did on first shift, but when I came back from my suspension, first shift wasn't. They'd get them up and change them, but then again they wouldn't change them until noon or 1:00. Well, if first shift doesn't change and second shift doesn't change, that's going eight to ten hours without checking and changing anybody. And if you were to see sitting in urine or feces for that long, you'd end up, in a period of time, getting bed sores or some kind of inconsistency there on your bottom you'd be sore all the time. Just something I wouldn't want to be in. You know, if it were me, I would like to be checked and changed or taken to the bathroom every two hours. I've heard that you guys have been talking about the overtime, which first shift picked up a lot of overtime hours, and a lot of those hours are from...on second shift, because they

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do want to have familiar staff on living units because some of the living units, if you don't have familiar staff, you have more behaviors. Well, the one...I put in 64.5 hours of overtime during Christmas and...Thanksgiving and Christmas, but it's more, it's not asking, told that we really, really need familiar staff, making you feel guilty because you don't have it. But then on Christmastime it was the manager and myself and I called my daughter to come in and help us, which she was currently working out here too. So you have three staff at Christmastime and we work so short. It's just horrible. But the overtime is outrageous. I mean I would put in my three days of overtime and I would sign up for more overtime just so I wouldn't be froze. Then the staff are expected...I'm just going to go on from my list. I'm going to try to keep it short, if I can. And DTIII staff are expected to go to the IDT meetings and behavioral management program meetings with the psych clinics and that and...but our manager wouldn't be there most of the time. You know, she told everybody that she's usually there at 10:00 and she never shows up until 11:00 or 11:30. So we're going to these meetings and trying to inform her, which I do have papers that Jeni has copied off that are up in Senator Wallman's office, (inaudible) stack of papers that, at any time, if you all would like to look at them that would be wonderful. Trying to think of what I'm going through here. I was the only regular staff on 303 for a very long time. I was doing a DTIII position but not getting paid for it, so my manager told me to apply for it. I applied for it twice. And when I was suspended, I had made a comment to HR about it and she told me to apply for it again. I said, well, I'm not even going to do it anymore because I was doing the menus for family style dining. We were doing the community integration, setting up trips to go grocery shopping. I'd help set up appointments. I would pretty...I did inventory. I did a lot of things for that living unit. I ordered all the briefs, treatments, trying to teach other people how to do it, and was...had gotten in trouble for that because it wasn't my position to authorize that, but the manager wouldn't authorize that to anybody else either. So you try to, instead of getting too much on your slate, I was trying to split it out because second shift just did not have time to do any of this for us because they were, quote, quote, in their eyes, so busy that they couldn't do it. And they're "so busy" is pretty much sitting in the back by the desk in a client's chair with their feet up watching

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TV or going into the individuals' rooms watching TV, you know? So a lot of what started, I was targeted then because I had turned second shift in for having knives to the CEO and they were hidden in the ceiling, and you're not supposed to have anything but corrugated knives. We're not supposed to have a sharp knife so in case something happens to where one of the individuals would get them and they would get hurt. But they had them anyway. The knives were...I had one of them one day and the manager's sister found it so she took it to the manager. Well, in turn, these knives got somehow back on the living unit and were hidden up in the ceiling. So I went to the CEO about them and he had somebody go over and take the knives out. Nothing was ever done. All of us could have been fired for having those knives on that living unit. Another thing, we are trying to retrain one of the individuals to feed himself, and my coworker that was suspended with me at the time, had him...slowly had gotten him turned around to sit at a table and pick up his cup. Because when we first got him on the living unit he could feed himself, but then we ended up feeding him in a chair. Well, then I don't remember who it was said that we needed to have him back at the table, so we tried to retrain him and he started doing pretty good. But people don't...they don't want to do the training. You know, you get trained in classes on active treatment, your behaviors and this, that and the other, and people just, I think, forget or just don't want to do it, plain just don't have the patience to do it. On my suspension, I was suspended for abuse and neglect on an individual, which never happened and it was unsubstantiated at the end of everything. I was suspended for five weeks. During that time I was suspended, another coworker of mine that worked on second shift, from what I hear, was...and I know it's all hearsay, was suspended for two weeks, but he did get to come back before I did. He was only...and how bad is abuse/neglect if you're going to get suspended? Everybody should be suspended for the same amount of time, whatever, and brought back. They say, oh, you should be back in about a week or two. Five weeks later and you're still wondering, do you have a job? You know, once you're targeted, you're targeted and they don't give it up. But in part of this, the suspension process, my manager, I feel, did not follow the BSDC policy because right here it states that the team leader or designee ensures the accused employee is removed/separated

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from all client care contact. She left my coworker and I on the living unit for 30 to 45 minutes. I ended up giving him his acetaminophen and putting a band-aid on his leg. So if I was so abusive to this client to begin with, because he has behaviors where he scratches his legs, why would I have anything to do with this client? We were removed, 30 to 45 minutes later, off the living unit into the conference room there on C Building, and I asked the investigator, I said, are we suspended or what? He goes, you mean your manager didn't tell you? And I said, no. So, you know, there's...I could go into a lot a lot of detail, but I'm not because you guys do have a lot of this paperwork, like I said, with Jeni at Senator Wallman's office. And I don't know, Senator Wallman, if you've read any of that part. There's a lot of information there. You know, our community integration is something that we need to go through and we are supposed to do, and five of my trips were cancelled. So, you know, it's...I just don't know anymore. I loved working here, but I ended up quitting because, like I said, once you're targeted, you're targeted. Confidentiality is broken here by all aspects, starting from the CEO all the way down. When I went to the CEO, I gave him...he made copies of papers that I had. I have received two phone calls that I have talked with Jeni about and one of them was to tell me that it was stupid and petty for me to turn in these two guys on 303 second shift for the knives, and the manager, that I must be dumb or stupid or that I was wanting a death wish, because apparently the CEO has let certain people know exactly what him and I have talked about and who I've called out here at BSDC to talk to, which I've called three people: the CEO, HR, and a nurse. So if...you know, how did these people find out everything? Confidentiality, it's just broken. I think the last thing I'd like to say is managers and some of your professional staff take the DT staff training to be able to work on our living units to help us out during shortage times in staffing, and that's wonderful. That is just...it is wonderful. But if they're going to take the class then they should be able to do the DT training part of it, not just part of it but all of it, because that's what is expected of us when we do that. And I think that's pretty much all I have. []

SENATOR LATHROP: Okay, Pam. Did you say you still work here now, or that you left?

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PAM MEYERS: No, I don't. I ended up quitting. []

SENATOR LATHROP: You left. Okay. Senator Harms has questions for you. []

SENATOR HARMS: Thank you, Senator Lathrop. Pam, thank you very much for your testimony. Would you explain to me why you think you were targeted? Is it because you (inaudible) the administration, management? Why do you think you were set aside and targeted? []

PAM MEYERS: Because you get targeted as a troublemaker and once they think of you as a troublemaker then they just target you. []

SENATOR HARMS: And a troublemaker in what way, Pam? []

PAM MEYERS: Well, it all stemmed from the knives, when I turned in second shift, because on that new living unit second shift can do no wrong, first shift did everything wrong. []

SENATOR HARMS: Thank you. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Thank you, Pam, for giving us your thoughts here. []

PAM MEYERS: You're welcome. []

SENATOR STUTHMAN: A thing that really concerned me when you was talking at the beginning of your testimony was the fact of, you know, the changing of the... []

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PAM MEYERS: Individuals? []

SENATOR STUTHMAN: ...of the individuals and your complaint, you know, that the prior shift hadn't changed and stuff like that. Why didn't, you know, management or people above you trust that you were saying the right things and that they wouldn't check on the other individuals, you know, a half hour or 15 minutes before that shift quit to make sure that, you know, what you were saying was right? Was there ever anything done like that? You know, if your shift started at, let's say, midnight, why...and you said they weren't changed and, you know, at a quarter after 12:00 they were...everything was wet, or they were dry but everything underneath was wet, like you stated, why wasn't there ever anything of management to have trust in you that what you were saying was right? []

PAM MEYERS: I don't know. I went to my manager about a lot of things. She could have just thought, you know, I complained too much or whatever. But, you know, I'm getting older, I'm not getting any younger, and I'd like to, if I'm going to end up in a nursing home, I would sure like to find one that's going to check and change me every two hours and take me to the bathroom. These people out here don't deserve that. They don't know, you know? It's just not right. I work for agency staffing throughout Nebraska right now and I got to Hebron, I go to Lincoln and I go to Seward, at the time being, and I have traveled clear out to western Nebraska. This isn't the only place that you see it at. There's several places out there that you do. It just takes the people that really do care to try to make people understand, you know, if this was you, would you want to be this way? []

SENATOR STUTHMAN: Thank you and I really appreciate your testimony. []

PAM MEYERS: You're welcome. []

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SENATOR LATHROP: I think that's it. Thanks, Pam. []

PAM MEYERS: Uh-huh. []

SENATOR LATHROP: Have you had a chance to fill one of those forms out? []

BRIAN ADAMS: No, I haven't, but I'll... []

SENATOR LATHROP: You can...we'll let you fill one out after you talk, if you promise to. []

BRIAN ADAMS: Yeah. It takes me awhile because I shake a lot anyway. []

SENATOR LATHROP: That's all right. That's all right. Why don't you tell us your name and spell your last name for us, please. Why don't you tell us your name and spell your last name for us. []

BRIAN ADAMS: My name is Brian Adams, A-d-a-m-s. I work on 413 State. There's some things that I agreed with and some things I didn't. And to let people know right now, I got one of the biggest mouths out here. And as for being targeted, if...me and the CEO don't see eye to eye on a lot of stuff and if they targeted anyone I would have been gone a long time ago. As for Senator Harms, you know, as for staffing, staffing I'd have to say is not the best out here. We a lot of times we might schedule trips and we have to cancel trips because we don't have...and a lot of times we're told...we're told, well, we can't use that for an excuse, because we don't have enough staff, because we don't have...we have to cancel trips because we don't have enough staff, and we don't. We don't have enough staff. And the mandatory overtime, I have a wife. I work second shift. My wife works third shift. A lot of times there's been times where she'd get held over three days in a row. I mean that's kind of too much for one person, especially when she's held over to pass meds, pass medication. I mean that's not, in my eyes, that's not

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safe for the individuals when you're passing medication and you're held over and you have to pass medication to the individuals. That's not safe for the individual. Okay. But on the other hand, I have...the staff here, I have seen the staff, they treat these individuals top line. They treat them real good. They go out of their way for them. Myself, I have seen individuals were...say if the staff...there's something...an individual can't...is doing something where this staff don't...the individual is acting up and the staff can't handle them, the staff is smart enough to go, okay, well, I can't do nothing with this individual, but I know this staff over here is able to do it. And say I'm the staff that can take care of them. They're smart enough to come over and get me and I'm able to handle them. And there's been lots of times that's happened. They go out of their way for them, and I seen this many of times. I've worked two units since I've been out here, and I've been out here since 2001, and so it's been seven years I've been out here. I've been all over this country and I have been many different places, and this place, I've had my heart broken many times out here when I see the individuals pass on. You know, I've never cried so much when I see some of these individuals pass on. I just bawl my eyes out. And...but, you know, the staffing out here, you know, I'd have to say about 80 percent of it out here is lack of staff, and the other 20 percent is maybe the way the place is, you know, the place is...the way they handle the staffing, the way they (inaudible) the staff (inaudible). Okay. But as for retaliation, you know, if they were to retaliation on, you know, the staff, I would have been gone a long time ago. But they treat, you know, the staff out here treat their individuals great, unlike, I don't know if he's...yeah, right there, we go out of our way, you know, like what he said. We throw ourselves under them when they're falling, you know, so they that they don't get hurt, because that's what they expect from us. And, you know, and we...I mean, you can say a little and get a lot out of it, you know, and I don't have much to say, but, you know, you guys go ahead. []

SENATOR LATHROP: Good. Thank you for your testimony. We'll see if there's any questions for you, Brian. Yes, Senator Stuthman. []

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SENATOR STUTHMAN: Thank you, Senator Lathrop. Brian, when you stated that when one individual...when one staff member maybe needs help in a situation and you could call on another staff member and come over and help, would that other staff member ever be disciplined for leaving his area to assist you? []

BRIAN ADAMS: No, because they would...we'd switch over. []

SENATOR STUTHMAN: Oh, you would switch over. You would trade, in other words. []

BRIAN ADAMS: Yeah, on the unit, yeah. You know, we'd switch over. We had an individual...the staff would be over here taking care of somebody else and so that staff would come over and take care of this person. []

SENATOR STUTHMAN: But that other staff person wouldn't be disciplined for trying to... []

BRIAN ADAMS: No, because the individuals are still being taken care of. You know, we just...we're taking care of the individuals and it's better that the individuals are taken care of instead of...because if you're not switching over and that individual is...and that individual is getting upset, you know, he's going to hurt someone. You know, this individual can probably handle them better...or this staff can handle the individual better. It's better to have that staff over here rather than to see someone get hurt. []

SENATOR STUTHMAN: But you feel it's never happened where they've disciplined the two individuals for switching jobs or anything like that? []

BRIAN ADAMS: Not on that...not on the unit where I worked at, but I have...I have seen it on other units. You know, I have seen other people get disciplined on other units where it's happened. But on the units I work...on the unit I work, because I have, you know, on the unit I work it hasn't happened that way. So, you know,... []

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SENATOR STUTHMAN: That was the concern that I had, you know. And I think, you know, what you're doing in your unit, you know, is the common sense thing to do when you know someone else can maybe handle that resident. But you have...you did state that, you know, some other ones would probably get disciplined. That's a concern that I have, so...but I think you were doing the right thing and I appreciate that. []

SENATOR LATHROP: Any other questions? I don't see any. Thanks for your testimony.
[]

BRIAN ADAMS: Okay. I'll get this filled out. []

SENATOR LATHROP: Yeah, that would be terrific if you would. I think we'll take a ten-minute morning break just to give everybody a chance to move around and use the rest room if you need to, and we'll be right back. []

BREAK []

SENATOR LATHROP: Again, if you don't mind, if I can though...if I can have your attention for just a second, I am told that more people are getting forms and filling them out, which tells me that we'll have more than the few five or so people that raised their hands, which is really good. We truly...the more we hear from people that work here the more we'll learn. But the more people we have testify, the more we're going to ask you to try to keep it somewhere in the ten-minute range. Kind of tell us what you have to say. We do want to make sure that we have enough time through the course of the day. I don't know how many people are going to testify, but if you can kind of...we're not going to stop you or...unless it gets going on too long, but we want to make sure that everybody has a chance. So again, feel free to testify and fill out a form before you do. Okay. Thanks. []

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LINDA CULLISON: My name is Linda Cullison, it's C-u-l-l-i-s-o-n. I worked out here about...a total of 37 years. I've been a DT staff and now I'm in the developmental specialists office, which I do the schedules, their time. I set up every morning. I call the living units at 6:30 to make sure the staff is there, whatever, if I have call-ins and to make sure there's enough staff on the living units. When I started back in '67, the quota, you had about two staff on a living unit for 16-17 individuals. It's changed a lot, lots of changes through the years, lots of good things, lots of, you know, we went through a time, a bad time, but now I think we're getting back. We're getting more good staff. Our staff out here is awesome. They're awesome. They, you know, they are very good with the individuals. Out of my office, I'm seeing a few things different and I'll just tell you a thing that happened to me today about the freezing and the holding over. You're supposed to call in an hour before first shift if you're sick, two hours before second shift if you're sick, and that don't happen. I got a phone call at 6:00, 6:15, and 6:20 today, and I already had my setup for my staff on the living units where I wasn't going to have to do anything. I had to freeze at the last minute, at 6:20. Well, that's where you're getting where staff are not happy with you, but that's not our fault. The rules all have to be the same. All the staff have to understand the rules are the same. There are not any exceptions, like it has to be 5:30 when you call in, because if you don't, you make it hard for everybody else to get staff on the living unit. There's a...not a lot, I shouldn't say. There's some sick time abusers and I don't know what happens after we'd let them know out of our office. That's not...I just let the uppers know. But I guess when you set up, as for campus I did all myself today, you have to look at the whole picture, because all these individuals have to be taken care of. You can't just look at one unit and say, you know, we need four staff today. If they are only...need three staff, there is a pull, to pull to care for somebody else. But they, you know, and I understand the staff. They have their units, but it's the whole campus. It's all the individuals that need care. So I better stop because if I don't I'm going to go over ten minutes. []

SENATOR LATHROP: Well, that's not a hard rule, but it sounds like you have a very difficult job. []

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LINDA CULLISON: I do. []

SENATOR LATHROP: And you have folks that call in and... []

LINDA CULLISON: I had one at 6:00, 6:15, and 6:25 today. []

SENATOR LATHROP: What time does the shift start, at 7:00? []

LINDA CULLISON: It starts at 6:30. []

SENATOR LATHROP: Oh, 6:30, so people are calling in the last half hour saying I'm not coming in today. []

LINDA CULLISON: Yeah. And then you have people...one more thing. The mandatory thing, the overtime, it has gotten lots better. It's not like it used to be, and I think you ought to be able to see that if you get the things head ups down here. The holding, that is nothing that can be helped, because when you have living units that don't have one staff on it this morning, what was I supposed to do? []

SENATOR LATHROP: Okay. It sounds, no, you know, it's...I'm listening to your testimony and it sounds like you think we blame you for it. []

LINDA CULLISON: No, I'm not blaming. I'm just, you know, no, don't, don't, no. []

SENATOR LATHROP: No, we're not. We're not. I want you to know that. []

LINDA CULLISON: No. No. (Laugh) []

SENATOR LATHROP: I mean it's...but it does seem to be a fact of life. It does seem... []

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LINDA CULLISON: I want you to...I want you to know that it's a fact of life. When people call in that late to get living units covered, we don't have no other choice. I am not going to let a living unit with one staff take care of 15 individuals. I have to freeze. I think the staff...the staff don't understand the whole picture, the whole campus. It's just not their living unit or it's just not you need to go home at 6:45, your shift ended, because there have to be people that take care of these individuals. []

SENATOR LATHROP: Well, you've described your position and you are the development... []

LINDA CULLISON: Developmental specialist. []

SENATOR LATHROP: ...developmental specialist and, essentially, your job is to make sure that you've staffed all of the units adequately each shift. []

LINDA CULLISON: Yeah, I do. We do the schedules out of our office. They go out, most of the time, with fours on every day. []

SENATOR LATHROP: What's that mean? []

LINDA CULLISON: That mean four staff on each unit. []

SENATOR LATHROP: What's the proper staff for that? I mean what's the...if we were to do it correctly, is four the number or is five the number? []

LINDA CULLISON: Four is the number on some units, five is the number on some other units, six is a number on some other units. We have... []

SENATOR LATHROP: All right. And I'm shifting gears on you a little bit while I ask this

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question, if you don't mind, but when you start out, do you start out and do you have scheduled on each floor the proper number of staff? []

LINDA CULLISON: Unless we have call-ins. []

SENATOR LATHROP: So to start out with, you...to start out with... []

LINDA CULLISON: Most generally, we have four every day. []

SENATOR LATHROP: And what I'm looking for is are staff at four the ratio of staff to residents... []

LINDA CULLISON: Uh-huh. []

SENATOR LATHROP: ...is the correct ratio. []

LINDA CULLISON: Right. []

SENATOR LATHROP: That's what you... []

LINDA CULLISON: Yes. []

SENATOR LATHROP: That's the optimum. []

LINDA CULLISON: Uh-huh. []

SENATOR LATHROP: Yes? []

LINDA CULLISON: Yes. []

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SENATOR LATHROP: And the...so the overtime comes and the problems with staffing come with the call-ins. []

LINDA CULLISON: Oh, yes. []

SENATOR LATHROP: So people call in sick and you have to...you require folks from the previous shift to stay over another eight hours. []

LINDA CULLISON: Well, and this morning it was because three people called in after 6:00. []

SENATOR LATHROP: I got that. []

LINDA CULLISON: Okay. []

SENATOR LATHROP: Believe me, I understand. (Laughter) []

LINDA CULLISON: Well, because I... []

SENATOR LATHROP: No, I don't...believe me, I'm not making light of it either. And I understand that part of your world that you live in and the difficulties. I'm wondering is that something that we can correct by having standby staff or people that you can call to come in and work. []

LINDA CULLISON: Sir, I called everybody I could today. Matter of fact, none of the overtime is here anymore because I worked all morning before I came down here and got them out of here. []

SENATOR LATHROP: So that's instead of assuming that they work another eight hours, some of them just work two hours... []

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LINDA CULLISON: Right. []

SENATOR LATHROP: ...till you can get somebody else in. []

LINDA CULLISON: They were out of here all by 9:00. []

SENATOR LATHROP: Okay. You mentioned that you have sick...people that call in sick and abuse that. []

LINDA CULLISON: Right. But I don't know where that goes after my office. We let people, the higher ups, the managers and them people, know about that. []

SENATOR LATHROP: How prevalent is that practice? []

LINDA CULLISON: You know, I don't call them up and ask them what they've done with it so, you know, they might be, you know, disciplined and I don't know it. But the call-ins today are people that call in. You know, I have over 1,000 hours of sick time, you know, and I guess people don't understand, you know, when you have that sick time how important it is because if you'd ever get sick, I could be off a long time. []

SENATOR LATHROP: Yeah, if you had a chronic illness. []

LINDA CULLISON: Yeah, and my husband does so, you know, some time I might need that time. []

SENATOR LATHROP: Are you the person that calls, if I'm a DTIII working over on a particular unit, are you going to call me? You're the person that makes the phone call? []

LINDA CULLISON: They make the phone call if they need more help or something, yes,

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I'm it. []

SENATOR LATHROP: Well, let's say that somebody calls and they're supposed to be on unit number four... []

LINDA CULLISON: Right. []

SENATOR LATHROP: ...and they call in sick and you say, well, I got to have somebody because we'll be understaffed if I don't. Do you have to call over to that unit and say, hey look, Joe,... []

LINDA CULLISON: I call... []

SENATOR LATHROP: ...today is the day, you got to work. []

LINDA CULLISON: Today is the day. I call the living units every morning on... []

SENATOR LATHROP: How are you received when you make those phone calls?
(Laughter) []

LINDA CULLISON: Today not well because it was...I usually try to freeze at 5:30 when I get all my call-ins, but all my call-ins were after 6:00, so that's when it gets really difficult because you got to do it. Unless you... []

SENATOR LATHROP: I know you have to do it. My question was...no, and I really do, I appreciate what you're telling us and the difficult spot that you're in. My question, though, had to do with how you're received. And you're call... []

LINDA CULLISON: Not well. Not well. []

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SENATOR LATHROP: ...you're calling some mom who may need to get home to take care of... []

LINDA CULLISON: I've heard all that today. []

SENATOR LATHROP: ...get the kids to school. Yeah, I need to get my kids to school. []

LINDA CULLISON: Right, and I... []

SENATOR LATHROP: They don't have a ride if I stay. And you say, we don't have a choice; we can't leave the unit understaffed. []

LINDA CULLISON: No, I didn't tell them that. I told them that I'd get them out as soon as possible today, and one I got out really fast because I had somebody walk in, an on-call walk in my office. And, like I said, the rest of them got out by 9:00. []

SENATOR LATHROP: You did your job well, but my point is we're also talking about what it's like to work here and from the point of view... []

LINDA CULLISON: It is... []

SENATOR LATHROP: ...from the point of view of the person that gets that call at 6:15 that they now have to stay... []

LINDA CULLISON: Okay. You know, yeah. []

SENATOR LATHROP: ...they got 15 minutes to sort their family stuff out. []

LINDA CULLISON: Yeah. Okay. But I look at it, we're here to take care of all the individuals. I am here to take care of getting staff to take care of the individuals. Now I'm

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sorry that happened, I really am. I, you know, I had a terrible morning, but I really am sorry that it happened. And that's why I keep on working to get people out as soon as I can. And, you know, there was a unit with an extra today because they were having a terrible time with some behaviors, and I left them because the manager called me and asked me if I could, so I did. But, you know, that was the only extra person I had. []

SENATOR LATHROP: Do you sometimes leave a unit understaffed? []

LINDA CULLISON: Never. []

SENATOR LATHROP: So... []

LINDA CULLISON: In a situation...well, I can mention something that happened the other day, but I told the staff to go to a different unit. Well, it took her a little longer than just a few minutes, because I got a call from the manager, and we still don't know where she was at, but she finally got there an hour later. []

SENATOR LATHROP: She didn't go straight there apparently. []

LINDA CULLISON: Right. Supposedly, she took a lunch break. So that isn't something that can always be helped. You know, we do the best we can out of our office with the staff we got. []

SENATOR LATHROP: Do you do any of the hiring and the firing? []

LINDA CULLISON: Oh no. (Laugh) No. []

SENATOR LATHROP: Okay. Okay. It sounds like you got your hands full with the job you do, scheduling. []

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LINDA CULLISON: Well, I enjoy my job very much and, like I said, the DT are awesome. I mean there's very good DT staff out there. And some of the new hires that we're getting are, you know, are very good. You know, I teach the CRONOS (phonetic) class in orientation every Wednesday morning and get to meet the new staff and there's some really good ones. []

SENATOR LATHROP: All right. I'll see if anybody else has questions. Senator Gay. []

SENATOR GAY: Thank you. Linda, who is your supervisor? []

LINDA CULLISON: Rhonda Penner. []

SENATOR GAY: Okay. How long have you been having this problem? I mean it... []

LINDA CULLISON: What do you mean problem? []

SENATOR GAY: Well, when you have to call people in. []

LINDA CULLISON: I really don't have a problem. It's just the problem when... []

SENATOR GAY: It's not for you, (inaudible) for the employees when you call them and tell them. []

LINDA CULLISON: Huh? []

SENATOR GAY: Probably when you call them and say you got to work overtime. []

LINDA CULLISON: No, I don't...I just, you know... []

SENATOR GAY: Has it been worse or is it getting better? []

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LINDA CULLISON: Well, yeah, it's getting much better. It was worse when I had to freeze every morning, and I haven't froze for a long time. This has been the first day in a long time. []

SENATOR GAY: Okay. So (inaudible). []

LINDA CULLISON: We're getting staff, good staff. I don't see that it's a problem. It goes back to any...just like any other job. You have a job to do. You work at a factory and they say you have to work 16 hours. You know, it's to take care of these individuals. And my family all works at factories and they do that. They make you work Saturday and Sunday someday. It isn't that, you know, we want to, not at all, because I like people to have time off. But it's that we have to take care of these individuals out here. []

SENATOR GAY: Yeah, which I think your dedication is commendable, like everybody here. I think there's a lot of great employees. []

LINDA CULLISON: You know, we were short in our office. I was working 14 days straight, you know? So be it. []

SENATOR GAY: So how did...in your mind then, you're saying, well, we didn't...the problem is getting better. How did that problem get corrected and how could it continue to improve? []

LINDA CULLISON: We're getting staff. []

SENATOR GAY: So it's a staffing problem. []

LINDA CULLISON: Yeah. I mean, we've got quite a few new staff. I wouldn't have any number but, you know, a lot of first-shift living units are full. There's not too many empty

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slots on first shift. I'd say maybe ten, you know. []

SENATOR GAY: So are you feeling better about your position then, is what you're saying? []

LINDA CULLISON: Yeah. Well, you know, I like my job. []

SENATOR GAY: Yeah, I can tell that. That's great, by the way. That's awesome. So you're feeling better about the long-term problem. []

LINDA CULLISON: Right. Right. []

SENATOR GAY: All right. That's all I was getting to. Thank you. []

SENATOR LATHROP: I don't see any other questions. Thanks for coming down. []

LINDA CULLISON: Thanks. []

SENATOR LATHROP: Appreciate it. []

BARBARA HUDSON: My name is Barbara Hudson and I work on 412, and I also work part-time at Mosaic. I'm also a single mother of two small children. There was an episode where I was suspended. I was suspended for 30 days and what had happened was, was that somebody thought that I had said something I didn't say it. It was somebody else that said it. Okay. So he wrote up his statement; I wrote up my statement. And I had used a slang word. What I was trying to do was to get a client's attention. It was a very loud. It was very noisy. I could tell that he was about ready to fall down. And so I didn't...I said in a firm voice, please sit down, you're going to trip over your fricking feet. I used the word "fricking." Okay, there was a gentleman that I don't even know where he even came from and it was another person, I think, that had said it

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and I think it was the person who actually fell down that I was trying to catch had said, I tripped over my dumb feet. Okay, at that point in time, I got suspended. I wasn't separated or anything. I took care of the individual. He had a scratch and I...scratched his knee. I can't really remember now. But anyways, because I wrote up my statement and I used the slang word, I was punished for 30 days. During that 30 days, I was to stay by the phone and to wait. And because of this, I had to use six days of vacation time. I couldn't work at my other job, which is Mosaic, because I was labeled as an abuser. It doesn't feel good to be labeled like that. It doesn't feel good at all. What I was trying to do was to have him wait until I can assist him to stand up. Well, during break time, other people get up, they want their money for pop, people are trying to run programs. Harry is a very large gentleman and he did go down. But because somebody thought they heard me say something, that was the original reason why I got suspended. When I wrote up my statement, and I was honest and I did use that slang word, I was suspended for 30 days. During that 30 days, I want to know who was doing my job. I've been working out here...it will be 28 years in September, 28 years. Never ever have I ever been in any kind of trouble ever. I've always gotten really good evals. I show up for work every single day. I work with basically the same gentlemen I've had for many, many, many years. And I do, I volunteer...might not volunteer, I do get paid for it, but I also say I can work this day, I can work this day if you guys are short, I can do it, because I do have children at home and I don't make a fuss about it. It's a job and you got to do it. Somebody has got to take care of these people. But being as many years at I have worked here, who was doing my job? Who can do my job as far as the diets go, the toileting goes, dressing goes? Who knows those residents? Somebody that was pulled over didn't have a clue about what was going on and I was labeled as an abuser because I had used that word and because I was honest. I was honest and that's what I wrote on my statement. But there was a big investigation about what are we going to do; are we going to use here for an example so we don't have any more slang words being used anymore? What's going to happen to the gentleman who can't button his shirt and somebody saying, you need to button your shirt? I know he can't button his shirt or tie his shoes, but yet, you know, you have people there that are unfamiliar with

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that living unit. And I really felt terrible about this. I felt awful about the whole situation because it was a big misunderstanding. Not only that, it's that I couldn't even work at my second job because somehow or another they had gotten wind of it and because I was labeled, which I felt that I was labeled as an abuser. Never been in trouble before in my whole life out of all the years that I have worked here, never, and then 30 days for this, 30 days. You're paying somebody probably to work overtime for my absence. And I know my job and I do it very well. I've always gotten real good reports--thank you very much for doing this--you know. The history with the gentleman, I mean, I could say, hey, I remember this happened six years ago, you know, and maybe we need to go back and see what happened in his history, why he's sick again just like he was. You know, it's just the history of these people. I take them to activities. I go...I've been to Girl Scout Camp, I've been to Boy Scout Camp, I've been to Special Olympics. I support those groups. I try and make sure that the gentlemen go down there and they have their fun, their activities. I take them to the dances that they have here. I've taken them shopping. I do their menus: What would you like to eat this coming weekend? You know, it's just these kind of things, and this is just part of my job that I do. But being suspended for 30 days of using a slang word and that I wrote on my statement because somebody, somebody overheard something and they weren't even...they were unclear about what they even heard in the first place. But it's just things like this that people get labeled for. And then you get the phone call, you get to come back, everybody is really happy to see you, but it's not I'm really sorry for this; I mean, I'm sorry that this happened. There's no...I don't know what the word I want to say is. It's just you just come in. You just come into your job and...I mean, the staff are happy to see you, the clients are happy to see you, but it's...we don't get anything by saying, I'm really sorry this happened, you know, it's a big misunderstanding. Does that make sense to you guys? []

SENATOR LATHROP: Senator Stuthman has questions for you. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. []

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BARBARA HUDSON: Oh. []

SENATOR STUTHMAN: Thank you for your testimony. I really appreciate it. The thing that I'm concerned about is when the management knows that there is a problem of staffing--and, you know, we realize there's a problem with staffing and it seems like we're always short of staff--and then they let an individual like you go for 30 days. That means that there's another individual short in staffing. []

BARBARA HUDSON: Yes, exactly. Uh-huh. []

SENATOR STUTHMAN: So they got to find one to do that or force other ones into more overtime... []

BARBARA HUDSON: That's right. []

SENATOR STUTHMAN: ...for something that I believe you're stating is, I thought I heard that. []

BARBARA HUDSON: Yeah. Yeah. []

SENATOR STUTHMAN: And that really bothers me. []

BARBARA HUDSON: And it really bothered me too. I mean I had a lot of phone calls when I was off saying, what happened; I can't believe this happened to you. And I was like, I don't know, you know? And at the time, I really didn't know what this other person thought that he heard me say when I didn't even say it. []

SENATOR STUTHMAN: Well, and the thing that management is just...someone says, I thought I heard that, because this guy said he heard it and that one said he heard it, and it's hearsay, and the top one says, out the door for 30 days, not even say, wait a

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minute, I got to find out for sure whether you said that... []

BARBARA HUDSON: Exactly. Uh-huh. []

SENATOR STUTHMAN: ...because you're important here and you're needed as staff. []

BARBARA HUDSON: Oh, well, thank you. Thank you. []

SENATOR STUTHMAN: So I mean that...I mean I'm jotting a lot of notes down but that does concern me when we're short of staff and then it's hearsay and you're suspended.
[]

BARBARA HUDSON: And, you know... []

SENATOR STUTHMAN: And that suspension will be on your record. []

BARBARA HUDSON: I know. I know. They tell me it won't be, but I have a feeling it probably will. And like I said, in September I'll be here 28 years and I think I'm a good employee. People tell me I've been a good employee. I show up for work every day. I run the programs. I do their medical needs. I've gone to check and change living units. I've gone to high behaviors living units. And it's just crazy, you know? And I think the investigator that had investigated me, I will say, was very kind and very, very understanding, you know, through the whole time that we were talking. He was an excellent person for me. []

SENATOR STUTHMAN: Okay. Thank you. Thank you very much. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: Thank you, Senator Lathrop. Robin (sic), do you think you were

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being targeted for any reason for this, with the suspension? []

BARBARA HUDSON: No. No, I do not. []

SENATOR HARMS: Okay. Good. Thank you. Secondly, if you are suspended, do you have the right to appeal the suspension? Can you, as an employee, appeal the suspension to a committee that could review this? Do you have any process like that? []

BARBARA HUDSON: You know, I suppose you...I really don't know, sir. I just don't know. I mean I was just glad that I could come back to work, that they found me innocent. []

SENATOR HARMS: You know, I just...what I'm really looking for is that if you feel like you've been unjustly treated as an employee, you should have the right to appeal that suspension, to bring it to the table. Do you have anything as far as the union is concerned that they can intervene to make this happen? Do you know anything...whether that's possible or...? []

BARBARA HUDSON: Yes, I believe it would be possible. I guess I just didn't really think of it at the time. You know, you just don't...I...for the first time ever being suspended, I really didn't know what was expected of me. I mean, basically they said, you know, I need to stay by the phone for phone calls. []

SENATOR HARMS: Would you had felt better if you would have had the right to appeal that immediately,... []

BARBARA HUDSON: Yes. []

SENATOR HARMS: ...to say, I would like to have this discussion, I'd like to bring people in? You ought to have the opportunity to face the person who is accusing you to say

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what was really happening here so that you could move this thing and get the truth on the table quickly. []

BARBARA HUDSON: Yes. Yes, exactly, yes. Yes, because I, you know, I wish it would have been done that very same day. []

SENATOR HARMS: Okay. Well, thank you very much for your dedication and I'm sorry that happened to you. []

BARBARA HUDSON: Thank you. []

SENATOR LATHROP: Senator Wallman has some questions for you too. []

SENATOR WALLMAN: Thank you, Chairman Lathrop. Yes, I appreciate your testimony here today. And regarding suspension, I can see where that is hard on employee morale and hopefully they take that off your record, and that concerns me a little bit. But it concerns me also the suspension, that a degree of verbal abuse, is that the same suspension as physical abuse or...? []

BARBARA HUDSON: I think abuse is just abuse. []

SENATOR WALLMAN: And that really bothers me. I mean, if you've ever been in the military, I mean, you've been called every name in the book. (Laughter) And so I think we have to look at the verbal abuse, but I guess that's a CMS policy probably. Thank you. []

BARBARA HUDSON: Yeah. []

SENATOR LATHROP: I think that's it. Thanks for your testimony. I appreciate it. []

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BARBARA HUDSON: Okay. I would like to say one more thing. When Mr. Potter was up here testifying, I had worked on a high behavior living unit just over the weekend and there was three gentlemen. For some odd reason, I don't want to get into it, but every one of those people had said, I can get...they weren't talking to me, but I can get so-and-so suspended, I can do this, I can do this. And so there are people out there, that's all they would have to do is just say, he kicked me, you know. But I just wanted to add that. []

SENATOR GAY: Hold on, I got a question. When you say "people," what are you talking about? Who can get who suspended? []

BARBARA HUDSON: The clients here. []

SENATOR GAY: The client knows I can get... []

BARBARA HUDSON: Yeah, the clients here, you know. []

SENATOR GAY: ...so I can get you suspended. []

BARBARA HUDSON: Yeah, they say, oh, I... []

SENATOR GAY: Okay. That's what I thought you meant but... []

BARBARA HUDSON: Yeah. And then that's it. Then you're gone. You're out the door. But I'll let you guys go, and thank you very much. []

SENATOR LATHROP: Thank you. []

TERRY BECK: My name is Terry Beck, B-e-c-k, and I work on 303 Sheridan, and I got a few issues of stuff. Senator Wallman's office has most everything I have here, so I'll

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cut it kind of short on it. We on 303 had problems with some of the DT staff. Like my coworker Pam, we both got suspended at the same time for...that's a long story. I worked with them one night on 1-23-08 and did not check and change. I worked overtime because I had worked the first shift, worked overtime till 7:00, but in the time they got there till 7:00 did not check and change, standing around clowning, and one of the guys was on the telephone doing personal time on rental properties and that, talking about rental properties and that. I brought it to the manager's attention. She tells me there's nothing she can do about it. Well, that's why I came to her. I mean, you're the manager; what are we going to do about it? Well, there's nothing she can do about it. I'll leave that there. Third shift, we got a third shift DT staff that brings her husband's work to work. He works in Wymore, reads meters. She brings his books and does his work on third shift, and that's why a lot of stuff don't get cleaned once in awhile. You watch her for days on end. Wheelchairs will still have some of the G-tube stuff spilled on it, not getting washed. That's been brought to people's attention too. And we seen, after we brought it to attention, she was still bringing those books to work. (Inaudible) have in here. We had a DT staff in there, one of the clients was...he had scoliosis in his back and sometimes when you feed him, he would refuse to eat that. Well, the DT staff would grab him by the forehead and say, I ain't got time for this, and he'd just start shoveling it in. And if he didn't want to eat then, then he'd take him, put him in his wheelchair, take him back to his chair and just plop him in the chair. Well, a guy that's old, frail, in his seventies, you don't just drop him in his chair, you know, especially when he's got a hunchback, you know? I'm just going to run through here fast. We had DT staff that has been there 20 years, you know, or so, one on one, with a client that had to be a one on one, falls asleep. You can't fall asleep with a one-on-one. When he's abusive, he hits people if he gets the chance. We have a client there that gets out the door once in awhile. He'll take off out the door. Well, I talked to the DT staff one night. I said, I hear he got out the door again. Yeah, but we're not supposed to tell anybody. Tell who, tell the people outside the unit or tell the people in the unit? People in the unit got to know so they know to watch next time in case he would want to get on. Well, he's done that many a times. One day we were running short on the unit and this DT staff, DTIII, he

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calls in, asks if we need a hand, and I told him, yeah, we could use an extra hand, we only had like two, three people there. And when you got a guy that's one on one, you know, most of the time, even with four people, one on one, that's three people there. Well, he comes in, punches in, asks them what guys he wanted to take care of, you know, and tell him we had this, this, this to do. Well, I ain't got time; I got to do paperwork for the manager and I got stuff I got to do for second shift. Well, then why did you call and want to come in if you're not going to help? Little overtime, you know, stops them from getting froze, you know? But do your stuff for second shift, then you ain't got much to do on second shift, which they only had one meal anyway. We on first shift, when I started going to first shift, we always got accused of we don't have nothing to do. We got two meals. We got training and stuff like that and haircuts we had to go do because when second shift would come on at 3:00 and that, they refused to take them down. Well, that's for you guys to do. Well, we got enough stuff to do, you know? Just running through quick. When I was suspended, we got a client there, has hearing aids, and we were doing dinner and I was up at the table feeding another client and this client, he sometimes is very demanding and he's not...he understands quite well a lot of times what he wants and stuff, and he was sitting there and the manager said she heard me from out in the hall. Well, a lot of times, even when a client has his radio on and turned up, I can't hear it out in the hall. People take break out there. Half the time you can't hear unless somebody opens a door. And I asked Charlie if he could wait a minute. Well, he has hearing aids and he, you know, acted like he couldn't hear. Well, they've been through the wash machine a couple times through his clothes and sometimes he plays with them. Well, maybe he couldn't hear that day and I had, you know, and I'm kind of loud anyway, but I had said a little louder, because there's noise going on in there, so he could hear me, asked him if he could wait a minute. Well, that's what caused me to get suspended, because I was yelling, I was screaming at him, which I wasn't. I was stating a thing, if he could just hang on a second because we were feeding other clients. Well, when I got suspended and then after I got fired, I was an on-call that worked 97 hours, 100 and some hours, worked a lot of hours. One morning I got called in to work first shift because they had two unfamiliar staff. I said sure. I come

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in. Well, that day I wound up working two shifts. I come in. Half the guys were at breakfast, only half dressed, some of them didn't have socks or shoes on, still in their PJs, some of them still in bed yet. I mean it was a total disaster that day. But I was an on-call part-time, but I filled in a lot because a lot of the other guys only ever did enough overtime so they don't get froze. Other than that, they always said, if I got to work overtime, I might as well get another job. And this is all on 3. The other units I don't know about. We just had a lot of stuff going on and we have turned it in, talked to the area administrator, talked to a manager, and just like nothing ever gets done about it. So when I got suspended, naturally, like I said, I got fired, you know. I went on unemployment. And I got a transcript coming in that if I can I would like you guys to listen to, because the statement that the manager gave over the phone--we had a court thing over the phone about the unemployment--they denied it because she came up with a whole new statement than what she gave the investigators out here. She said that she heard me say, but on her statement it says, I didn't hear what he said. She come up with a whole new one, you know? Other than that, just a lot. I said I was going to cut it short. There's a lot. Senator Wallman's secretary has stacks of papers on everything, basically, some of the stuff I covered here. And any other questions they know how to get a hold of me and... []

SENATOR LATHROP: Any questions? Senator Wallman. []

SENATOR WALLMAN: Yeah, thanks for coming. In regard to the suspension, you know, we've had some complaints about suspensions today. []

TERRY BECK: Right. []

SENATOR WALLMAN: And verbal abuse, is a lot of the suspension on verbal abuse, is it client abuse? []

TERRY BECK: Well, it was for me, but when you got a guy that has hearing aids that go

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through the wash machine, he plays with them all the time and you're busy at the minute, you want him to understand that he has to wait, how loud is too loud before it's yelling and screaming? And like the gal before me said, you know, there they go for something minor. But what about all this other stuff that nobody ever get...everybody gets turned in for that is major--checking and changing and that? I mean, I was just stating a thing to the client, if he could wait just a second, you know? And also, it got put on my termination paper about the scratches on his leg. Well, when you're feeding other clients and that, who looks at everybody's legs? I mean, you know? I'm sitting here looking at you. I'm not looking at your shoes or whatever, you know? I don't look at his legs all the time. But there was another gal right next to me that was feeding. Why didn't she get suspended? She was sitting there. She could have noticed that. But we got suspended for the verbal and the leg, so why didn't she? Or was she an "escapegoat," you know, for other stories going on to get us suspended? []

SENATOR WALLMAN: Thank you. []

TERRY BECK: Yep. []

SENATOR LATHROP: Think that's it. Thank you, Mr. Beck. []

DELVIN KOCH: My name is Delvin Koch, that's D-e-l-v-i-n and it's Koch, K-o-c-h. I'm currently the acting assistant administrator for area two. To give you a little bit of history, the campus is divided up into three areas, with three assistant administrators. I'd kind of like to shift the conversation a little bit and talk a little bit about some history first, and the first thing I'd like to say is I'm a 28-year veteran employee here at Beatrice State Developmental Center. When I began my employment here, I was 18 years old, basically I'll say a snot-nose kid who came in the door, college wasn't really an option at that time for me, and said I want a job. And I came in the door, hit the ground running, so to speak. I began my career at \$2.17 an hour and I thought I was going to be a rich man. But as I worked and I began to learn from the people that they paired me up with. I

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started as like the direct-care staff, worked several years at that. I was then given an opportunity then to work in the speech department, which was quite interesting. I learned a lot about sign language, a lot about audiology, that kind of stuff. I did that for a couple years and then I was able again, as that department was dissolved, I was able then again to go back and work on the units, working my way up to a DTIII type position. I was looked upon as a leader. I felt like the staff were comfortable enough to come to me to talk to me about any issue. I was able to resolve a lot of those issues without even going through management. We had a very cohesive team, not only on first shift but also on second shift, as well as third shift. We shared the responsibilities of the unit. We shared a lot of camaraderie. We even at times, occasionally, we socialized together and did things together. I felt through that experience and for what I contributed to that unit that I was able to move up to what we call an HSTS position. That's a human services treatment specialist type position. In that position then I was one notch up again further on the ladder and I was able to learn about writing different habilitation type programs for the individuals that we currently serve here at the facility, able to learn a lot about active treatment. I was able to learn a lot about scheduling, community awareness, and basic needs of all the individuals. I should back up. Also, when I started here, keep in mind there were approximately 1,200 individuals that lived at the facility and on an average day we had 38 individuals on one living unit with an average of three, maybe four staff. So you can see things have changed over the years. But again, as I was working as an HSTS, I came to a crossroads and knew that it was either go back to school or that's kind of where I was going to be. So through the facility, through the tuition assistance program and through other scholarships and stuff, I was able to go back to school and earn a bachelor's degree in human relations, which was...and I still don't know how I did it to this day because it was like working full time plus going to school on a three-quarter time basis finishing a degree within about five years. So it did work out well for me. The facility, again, was very, very good about I was working a lot of different flexible hours, I was working split shifts, anything to kind of make the classes work versus also continuing to do my job here. From that, once I earned my degree, I was able then to move into what we call the OAITs program, the Outreach and

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Intensive Treatment program, and I was able to get on the traveling teams, and that, I got to go out and I got to see community-based programs firsthand. What they would do is they would refer individuals to us with high behavioral needs and ask for our recommendations. That team consisted of a psychologist and generally two HSTSIs, which is, again, was one level up. So again, I got to see what I call the good, the bad, and the ugly. From that, I learned a lot in the two and a half years I was there. I learned a lot about the whole community awareness and the community-based type programs and how good they can be. I also learned how bad they can be. Along that way, too, then I also became involved with a parents' association and learned a lot about why they wanted their loved ones to be here and why they were scared of not having their loved ones here at BSDC. Through my experience with the OAITs program, I understood that very well. From that position, I worked that position for about two and a half years, and I was able to move up into what we call a QMRP position, qualified mental retardation specialist. And again, I began to learn how the team worked, how the team functioned, what they needed to do, etcetera, etcetera, to keep each living unit moving and keep each living unit on the right track. Very interesting position, lots of paperwork, learned a lot about the Title XIX standards and exactly what the facility needed to do to keep its doors open. At that time, I thought we were doing an excellent job. From there, I was asked then to step into an acting position as the area two acting assistant administrator. That covers eight basic homes that I have within a range of 12 to 16 individuals on each home, and a range of anywhere from 6 first-shift staff, 6 second-shift staff, to 2, sometimes 3 third-shift staff, 2 HSTSs, a QMRP, and a home manager. Now there's not a QMRP or a home manager for every home. Those are split. In the case (inaudible) those are split too. As we continue to downsize, we'll continue to do more of that. So you probably ask why am I telling you this story because it really sounds like, you know, really a novel story. What I want to say is, where did we go wrong? I was here in the eighties when this was one of the top-notch facilities. We had facilities around the country calling us saying, can you come and help us? You've done an excellent job. You've learned about five-hour programming. You've learned about active treatment. You've been through CMS. You passed CMS. What happened? What

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I want to say to this committee is I think that we began to rest on our own laurels. We got lazy. When I say we got lazy, in that, we had a lot of really, really good people that we were up in the...that worked up on the A Building, which is our administration building, as well as a lot of other good professional staff, and we began to rest on our own laurels. We didn't take that next step. Also, I kind of feel like our state surveyors let us down. There were a lot of changes coming within the Title XIX standards and how they were interpreted, and we weren't given that education. And by not getting that education, you can see where we are today. At one point, we were out six areas in the Title XIX standards. That is the worst and most unforgettable thing that I never want to see again. Why I say that and why I'm giving you all this information today is because I love this place. This is my career. I have a brother and I have a sister both at 27 and 28 years. It's their careers also. I have friends all through the town of Beatrice, Lincoln, all the small towns that come here. This is their career. And along with that career, this is their compassion. This is their...what I want to say is their...they have such respect for these individuals. I truthfully believe, now working with the hiring committee, that any staff person that walks through this door does not come through this door with a preset agenda to abuse someone. I truthfully believe that, yes, abuse can happen, but there is also a human behavior fact that factors into this. Example given: We had an individual who loved to play cards. She was pushed up to the group, handed some cards. She began to put the cards in her mouth. The staff person immediately redirected and took the cards away, and the individual began to cry. I truthfully believe that was a human reaction because she knew she didn't want the cards to be wet. Yes, some people say, no, that was mental abuse. You took that away from her. You took away something that she didn't...that she really liked. Again, it's an error in judgment call. Other abuse cases that I've seen out here, too: again, Barbara Hudson talked earlier, she used the word "fricking." In her family, she has, I know, ten brothers and sisters, that was a common term that they used--get the fricking heck out of here--because that was probably something that was ingrained to them by their parents rather than using the real word that you could use. So it's a human behavior. But again, she was once again accused of verbal abuse. These I know by the Title XIX standards though that abuse will not be

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tolerated. Each one is very well defined out in that we know exactly what they say by verbal, we know what they say by physical, etcetera, etcetera. And, yes, we do have to separate the individual immediately and, yes, sometimes those suspensions take up to 30-40-50, I've seen months where they go by. And it's very frustrating, it's very time-consuming, it's very upsetting to the employee. But right now our hands are tied. We have to. In accordance with standards, we have to do that. We have to do a thorough investigation. Yes, it's very, very frustrating. The other piece that is the confidentiality, a lot of times information is not given back to...maybe to the alleged abuser or to the other people on the team because of confidentiality. If I was accused of abuse, I would not want the information about my case going to everyone under the sun, yet it's a fine-toothed comb there of which way you want to go. As far as the good about BSDC, I wanted to talk a little bit about that too. I have seen many, many success stories. One that I will share with you: We had an individual who moved here from Lincoln in the early eighties due to the facility that she was working here being closed. She had some severe behavioral problems and lived on a unit here for a number of years. Her goal was always to come back out into the community. What we did is, on that unit she still wasn't have as much success, we moved her down to another unit. She lived there a year. We were able then to slowly integrate her back into the community for a wonderful success story. Now I also know some individuals that have lived here most of their life, have no desire to move. This is home. They do not want to leave this facility. Yes, we continue to try and place them. We continue to try and train people, the staff as well as the individual, for the skills that they will need to be able to live in the community, but it's a very difficult. I want you to know both sides of the fence here. It's very, very difficult. If today I looked at you and said, well, in the next year or so we're going to put you on placement, I'm sure most of you would say, forget that, I bought this home, I'm going to stay here, or I live here. But on the other side, I want you to be as independent as possible. What else do I have here. A lot of things, too, with the way that the abuse/neglect works, I think people have lost confidence in their own abilities. It's a very, very sad thing. We need to get people to get that confidence back and the only way to do that is to let them know that what they're doing is correct. Or if

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it's incorrect, we need to find another way, other than punishing, to correct the situation.
Questions? []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: Thank you, Senator Lathrop. Delvin, I might have misunderstood you. I just want to clarify this. You said that you felt like you were let down by the state surveyors. Is that what you said? []

DELVIN KOCH: That's correct. []

SENATOR HARMS: Could you explain that too? I guess I don't understand. []

DELVIN KOCH: I felt like that they should have been coming in and for years we had fairly decent surveys. Nobody wants to be flagged or said that they did something wrong and that, and so then maybe we weren't quite learning. And maybe we were let down a little by our QI department, too, in that we thought we were doing well, and so maybe we weren't going the direction that we needed to go. []

SENATOR HARMS: Where do these surveyors come out of? []

DELVIN KOCH: Lincoln, out of central office. []

SENATOR HARMS: Okay. And they actually come in and look at the operation, is that what you're saying is what's going on? []

DELVIN KOCH: Correct. And they probably were let down a little bit by CMS, too, in giving them the training that they need. It all comes back to a training issue. []

SENATOR HARMS: I would like to ask you just one final question. If you...you seem to

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be pretty knowledgeable. You've got, what, 28 years? []

DELVIN KOCH: Correct. []

SENATOR HARMS: If you had the opportunity to fix this, what would you say you would do? []

DELVIN KOCH: If I had the opportunity. []

SENATOR HARMS: If you had the power just to fix what we think is some of the issues, what would you do? []

DELVIN KOCH: First thing I would do is re-empower the direct-care staff. I would empower them and allow them to make decisions. I wouldn't allow them to abuse anyone, but I'd allow them make decisions, and then I would stick by them and empower those decisions and build from the bottom up so we get a good foundation going again. []

SENATOR HARMS: That's probably a pretty good recommendation. Thank you. []

SENATOR LATHROP: Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. I heard you mention the word "punishment," you know, like suspension. And that, I think, is terrible for 30 days, let alone 50 days, 60 days. I realize there's lots of stuff, but you can't category, like verbal abuse, I think a couple days would be plenty. []

DELVIN KOCH: Right. But again, our hands are tied by, you know, what we have to follow in rules and regulations. []

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SENATOR WALLMAN: Uh-uh, yeah. Thank you. []

SENATOR LATHROP: I would like to take an opportunity to have you maybe educate me a little bit on the disciplinary process, because, as I was reading the report...the reports, I...you know, they talk about all these examples of abuse and neglect and then the DOJ report really lists the truly unspeakable things. []

DELVIN KOCH: Uh-huh. Correct. []

SENATOR LATHROP: But that's...there are a lot of things that are labeled abuse and neglect that one may argue whether it truly is... []

DELVIN KOCH: Correct. []

SENATOR LATHROP: ...something that rises to the level of that label. []

DELVIN KOCH: Right, and that's why we have an investigations department, that needs to go through and really look at that. []

SENATOR LATHROP: You talked about your familiarity with the federal standards... []

DELVIN KOCH: Uh-huh. []

SENATOR LATHROP: ...and the federal standards you're referring to dictate how...first of all, that someone will receive habilitation while they're here,... []

DELVIN KOCH: Uh-huh. []

SENATOR LATHROP: ...that they will be treated in a particular manner,... []

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DELVIN KOCH: Uh-huh. []

SENATOR LATHROP: ...that...does that...do those standards also identify what is abuse? []

DELVIN KOCH: Yes, they do. []

SENATOR LATHROP: So this young lady that was here that said she used the term "freaking," ... []

DELVIN KOCH: Right. []

SENATOR LATHROP: ...in a statement to a resident, do the standards literally call that abuse? []

DELVIN KOCH: What it calls is...it gives you a definition of verbal abuse and... []

SENATOR LATHROP: Do you know what that definition is? []

DELVIN KOCH: Not off the top of my head. I don't have that with me. []

SENATOR LATHROP: Can you paraphrase it? []

DELVIN KOCH: It would say anything that was demoralizing to the individual that caused any mental abuse that...anguish that upset them in any manner. []

SENATOR LATHROP: Okay. So you can make a perfectly normal statement, if you typed it out it would not be abuse, but it's also in the tone? []

DELVIN KOCH: Correct, tone of voice, etcetera. []

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SENATOR LATHROP: Or it can be thrown in slang. []

DELVIN KOCH: Right. []

SENATOR LATHROP: And then that becomes verbal abuse. []

DELVIN KOCH: Correct. []

SENATOR LATHROP: Is that example that we saw, saying "freaking," you're going to "freaking" hurt yourself or trip or whatever the term was or the phrase was, is that treated the same as if someone kicked a patient? []

DELVIN KOCH: No, because that would then be jumped up. That would be physical abuse. []

SENATOR LATHROP: And so physical abuse is treated differently? []

DELVIN KOCH: Right. Well, abuse is abuse, no matter what. []

SENATOR LATHROP: Now I'm wondering about the consequences to the staff person.
[]

DELVIN KOCH: Right. And the consequences can be different, and those are defined out. We do have a set of definitions that we use in our abuse/neglect policy here. I believe is 4.1.1. []

SENATOR LATHROP: Oh, (laugh) we got the right guy here. (Laughter) If you remember the...if you remember the numbers of the different standards, that's pretty good. Here's my point. If you can, you can verbally abuse somebody by dressing them

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down and just really telling them that they're worthless and things like that, or apparently you can do that by using an angry tone while you're saying something like sit down. []

DELVIN KOCH: Uh-huh. []

SENATOR LATHROP: Fair enough? []

DELVIN KOCH: Uh-huh. []

SENATOR LATHROP: Are those treated the same in terms of the suspensions that will follow? []

DELVIN KOCH: Yes. Because everything is alleged and everything has to be investigated. That's why we have an investigations department. []

SENATOR LATHROP: Okay. So whether it's a... []

DELVIN KOCH: Whether I came up and I punched you in the nose or whether I came up and said, boy, you're a pain in the butt, it could potentially be treated exactly the same. []

SENATOR LATHROP: You will then be suspended. Your pay will be interrupted... []

DELVIN KOCH: Correct. []

SENATOR LATHROP: ...and you have to wait, pending the outcome of a hearing. And if I understand correctly, those hearings and that investigation may not be complete for...I think the average is 16.5 days or something? []

DELVIN KOCH: Right. The investigation is always completed within five days. Then it

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goes to what we call the investigations review committee where we look it over for thoroughness to see what's going on and then, if there are assignments to it, to make sure that those are fair and follow within the guidelines of our policies on that. And then it has to be carried out then depending on... []

SENATOR LATHROP: Here's...one of the complaints that I've heard from the employees' side of this, and again I have the advantage of having heard some of these folks testify in the Business and Labor Committee last session, but one of the concerns that they have is, as a professional, you can get the label of abuser, right? So if you want to go from here and try to get a job at Mosaic or a nursing home or somewhere else in the healthcare industry,... []

DELVIN KOCH: Right, I think... []

SENATOR LATHROP: ...you have that mark. []

DELVIN KOCH: ...what they're saying is, is if something is unfounded nothing will be placed in your file, but you still have that verbal rhetoric. Everyone on campus knows you were suspended. They may not know what you were suspended for and it can kind of follow you. []

SENATOR LATHROP: But it can follow you if your infraction is using a harsh tone of voice... []

DELVIN KOCH: Correct. []

SENATOR LATHROP: ...in communicating an everyday command. []

DELVIN KOCH: Correct. []

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SENATOR LATHROP: And then it makes it difficult for people to go get a job after they leave here. []

DELVIN KOCH: It can. It depends on what they put down for references. I know that our human resources department only releases certain information. You'd have to talk to someone there. []

SENATOR LATHROP: If you had...if you had somebody...do you do any hiring and firing? []

DELVIN KOCH: Yes. []

SENATOR LATHROP: So if you had somebody that was working at Mosaic and they had an abuse...a documented abuse in their personnel file at Mosaic, would you hire them here? []

DELVIN KOCH: No, it should go through our...it should be flagged after our personnel help do the records review and they also do a...I can't think what...it's a computer search so they can check to see if they've had any allegations against them. []

SENATOR LATHROP: Okay. And now it kind of comes back to this, in terms of why do I want to work at Beatrice if I'm going to get labeled as an abuser and... []

DELVIN KOCH: Exactly, and that's our biggest... []

SENATOR LATHROP: ...and now I can't...now I can't find a job anywhere in an industry that I went to school to be, say, a CNA? []

DELVIN KOCH: Right. People are scared. Why would I want to address my reputation on working at a facility that may accuse me of abuse? []

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SENATOR LATHROP: All right. Is the...is that label...when I was reading all this, it seems like we lump them all into abuse and neglect and there's no...there's no hierarchy, and it's abuse and neglect even if it's using a harsh tone to say... []

DELVIN KOCH: Right. []

SENATOR LATHROP: ...to say please sit down before you get hurt. Right? []

DELVIN KOCH: Uh-huh. []

SENATOR LATHROP: Is there a need for a different label, or is all of this dictated by the federal guidelines? []

DELVIN KOCH: I would love to see it all be broken out into various categories, but I think right now abuse is abuse. It's dictated that way, and that's the facility's policy also. []

SENATOR LATHROP: Okay. So there's nothing we can do as a state organization or an institution to change that. []

DELVIN KOCH: I'm not sure about that. []

SENATOR LATHROP: Okay. I think that's all I have. []

DELVIN KOCH: Okay. Thank you much for your time. []

SENATOR LATHROP: I see no other questions. No, thank you for coming down. You were very helpful. []

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LESA FAHRNBRUCH: Want lunch, or do you want short testimony? []

SENATOR LATHROP: Oh, it is noon. I was having...I was engrossed in the testimony and missed the fact that it's 12:00. How many more people do we have that are interested in testifying? Okay, about four or five, and I... []

LESA FAHRNBRUCH: Mine is real quick. (Laughter) []

SENATOR LATHROP: All right. Well, I guess we're going to testify before we go to lunch. (Laughter) We're an accommodating group too. []

LESA FAHRNBRUCH: I was just...I wanted to find out if there's any way we can get reclassified for, like, kitchen staff... []

SENATOR LATHROP: We're going to have to have you start out with your name and spell your last name for me. []

LESA FAHRNBRUCH: Lesa Fahrnbruch. []

SENATOR LATHROP: And, Lesa, why don't you tell us what you do or what you're...are you currently employed here? []

LESA FAHRNBRUCH: I'm currently employed. I work in the kitchen. []

SENATOR LATHROP: Okay. []

LESA FAHRNBRUCH: I've been here about 20 years. I feel...I worked on the living units for many years before I went to the kitchen, but the kitchen staff are getting robbed as far as pay increases. I don't know who makes all these decisions but there's a lot of people that haven't had raises in years. A lot of times things would come out and it's

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like, well, this area can get a raise and this area can get a raise but this area is not going to get one. And there's a lot of people that get overlooked for years. I don't know if people see the whole...the big picture of everybody. There is no incentives for being out here except for you love your job, you love the individuals you're here to take care of. There's no other incentives. There needs to be incentives. Somebody can get hired on the street and start making the same amount that I've been getting and I've been here 20 damn years, you know? We'd like to see our jobs reclassified so that we can get better pay. I'm not sure who would be responsible for that, but we'd like it looked into. And then as far as other testimonies that I've heard, coming from, in the past, working on the living units, I can testify that, yes, there is favoritisms and there is repercussions for things that you say. If you open your mouth and you say too much, there's going to be punishment to pay. It might be looking nice on paperwork that what they done to you was justified, but it's being done because you opened your mouth. The 303 incidents that were brought up by a couple of your past employees, I can pretty well say that, yeah, I fully agree with everything they said. Things get hidden on those living units. People team up with each other on different shifts. I just...most everything I've heard in the testimony is fully, you know, I agree with all of it. But my main thing was that we'd like to see reclassifications for the kitchen. The laundry department, that don't work with individuals even as much as us, they get more than us. How is that justified? I can't even begin to justify that. People get really upset, you know? And the suspensions, that's another issue. You can't say anything out of line because you're afraid you're going to get suspended, and you can't live without your paycheck. And you have a second job, like Bobby said, you're not going to have that second job if you're labeled. So that's it. []

SENATOR LATHROP: All right. Any questions? I don't think so. Thanks for coming down. []

LESA FAHRNBRUCH: Thanks. []

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SENATOR LATHROP: Now we need to deal with lunch. I think that...are there...is there a shift that's going to get over? Do you expect other people to come in that will want to testify in the afternoon? []

(WOMAN): Yes. []

(MAN): Second shift starts at 2:30. []

SENATOR LATHROP: So do you expect...if we broke from noon to 1:30, for example, are there going to be people who didn't raise their hand come into the room and want to testify? They're shaking their head yes in the front. []

(MAN): (Inaudible) 1:30? []

SENATOR LATHROP: No, between 1:30 and the rest of the day. []

(MAN): It's certainly possible. []

SENATOR LATHROP: Okay. Then rather than try to skip lunch and go through it, let's take a break. Okay, let's make it 1:00. I think we can probably get lunch in, in an hour. All right? Thank you. []

RECESS []

SENATOR LATHROP: We're, of course, having hearings. We're going to start with the afternoon. Again, the process for those of you that might have come since lunchtime, you're welcome to testify. We encourage you to. You have to fill a form out that gives us your information so that we can make sure the record properly reflects who's been here and testified. And when you take a seat, if you can give us your name and spell your last name for us. And the one thing I didn't say this morning that we should...I should

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pass along, especially given the beeps that were going off, if you have a cell phone, we'd like you to turn it off or at least turn it on vibrate so it's not interrupting or showing up on the audio. And with that, I think we'll start with our afternoon. []

JILL McCONNELL: I'm going to jump right up here before I lose my nerve. []

SENATOR LATHROP: (Laugh) Well, we're glad you had enough nerve to get to the table. []

JILL McCONNELL: (Laugh) To get to the chair. []

SENATOR LATHROP: Yeah. []

JILL McCONNELL: My name is Jill McConnell, M-c-C-o-n-n-e-l-l. I've worked at BSDC for 32 years and am looking toward retirement in the near future, if it doesn't come sooner than I think. But I wanted to, like Delvin did this morning, I wanted to give a little history because I think it's relevant in looking to the present. And I'm going to do it this way, starting with a very short letter I wrote to George Hanigan, Ron Ross, the then-Governor Johanns, Denny Byars in 2003. Some of those names might or may not be familiar to you. []

SENATOR LATHROP: Why don't you tell us who they are. We know who Johanns is, and I happen to know who Senator Byars was. []

JILL McCONNELL: Senator Byars from this district. Ron Ross, at the time, I'm trying to...was head of...in the way things were arranged at that time, which is different from now, I believe was head of DHHS... []

SENATOR LATHROP: Okay. []

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JILL McCONNELL: ...or the equivalent. And George Hanigan was, at that time, in charge of DD services in the state. And the letter says, addressed to Mr. Hanigan, do you know what...this is 2003, five years ago: Do you know what's going on at BSDC? If not, why not? And if so, is it okay with you? Is anyone going to stop the destructive process that's hurtling along like a runaway train, or are you just going to wait for impact and see what's left when the smoke clears? In almost 26 years at BSDC, I've never seen such inept management given free rein to create such havoc to the detriment of the people who live here. I have a sense of foreboding that it will end of tragedy for one or more of those individuals, as we struggle to provide care under increasingly uncontrolled circumstances brought about by recent restructuring and zone initiatives evidently approved by you. And I'll define those in a little bit or at least tell what I'm talking about. There are numerous details and observations which lead me to make these statements, but I won't describe them here in all their complexity. I figure if you are in the know you don't need to hear it from me. And if it's okay with you, what's the use? I'm driven to write this out of deep regret over the deterioration of BSDC from a once proud facility, with every reason to be so, to a very scary place for all. I'd be going through the chain of command with this communication, but the upper links of that chain here at BSDC are quite broken and useless. Every so often the thought occurs to me that there may be ulterior motives to this whole disastrous situation--perhaps a cowardly way of shutting this place down by letting it self-destruct. There wouldn't be any truth to that wild notion, now would there? Well, whether on purpose or by accident, it appears to me that the damage will be permanent. Those thoughts persist to this day and that situation persists to this day. In 2003, I mentioned zone initiatives and whatever it was called at the time, restructuring, and what those were, without getting really specific, were flippant changes in the organizational structure and service delivery here that were really similar to what Ben Nelson did, as he was leaving Nebraska, with Health and Human Services, and that was both here and there to provide or to create a system that was so convoluted, disconnected and top-heavy that accountability and excellence became qualities of the past. In each case, both with Health and Human Services at that time and with BSDC, I was struck by the impression, which I still hold, that many of

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those who landed in all the newly created, upper level positions were there because of self-interest and the buddy system, not because of education or experience or expertise or management skills or commitment to those needing state services and support. That is what...I could start as people have, you've already heard lots of the separate issues, separate problems, separate concerns here at BSDC, and people have expressed those very well, but my...over the past three, four years, I have come to the conclusion that unless we have a leader who has strong credentials and experience, who has creative energy and management skills to identify and work with us to solve problems and to set a direction and clearly communicate how we're going to get there, and who is unhampered by less qualified bureaucrats above him or her, the discussion of separate problems is going to get us nowhere. You have been really generous in finding money to fix problems. Now we have to find the person who spends that money wisely so that it really knocks out the problems, which I guess I feel pretty lucky that I was here when BSDC was growing into a superior facility. I was lucky. Now I am absolutely heartbroken to see that excellence go down the tubes. I believe that there has been some recent improvement in certain areas, but we're awfully reactionary with money and with decisions. They don't last more than a day or two. I believe the money is spent in a way that will not ensure that there's a solution at the end of the expenditure and that's very distressing. I think I will end with one little exchange between two people who have a long involvement with BSDC and this exchange has to do with the amount of money from your constituents, that includes me, that has been spent on consultants here at BSDC when, in fact, we have some superior people right here who could be doing the job for a lot less money than consultants have bilked us for. The exchange goes like this, and it was...took place in April of 2008: One person said, we certainly have been bleeding money that hasn't fixed any of the problems. Went to the goody shop today. The place was as crowded as I've ever seen it in years. All the temps, the extra staff that had been brought in from who knows where, were there eating lunch because it's part of their contract. I'm sure it's cheaper than giving them an allowance. Liberty, another...these...if these aren't familiar, stop me. Liberty will be gone by the end of the week, one lady leaves today, another Friday. Anthony Abboud, the abuse/neglect

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consultant, hasn't helped or at least it didn't take. Catherine (phonetic) and the other lady who came as consultants to QI didn't cause much of a stir or change. I'd be surprised if any of Liberty's changes will be kept for a month. (Editorial comment: Prediction correct.) Michael Smolz (phonetic) in-servicing has stopped. Haven't seen Amanda George (phonetic) who works for Smolz (phonetic) for a few months. Somebody else is coming back to BSDC tomorrow to do another investigator in-service because the first one didn't help us enough, and then there's always Randall Heinz (phonetic), who'd do the most damage, or was it John Worley (phonetic) or Vince and Conrad (phonetic), and then there are two names mentioned of people who are still here. The reply from the second individual says, I think you at BSDC are past a wound. Hopefully it's not a severed artery. I guess my main point is that as much as I appreciate your time and your willingness to take a look at this situation, and as valid as everyone's concerns are that they have enumerated, without proper management nothing substantial will be done. And when you have a mess to the degree that we have a mess here, you have to look really high as to where the source of that mess is. That's it. []

SENATOR LATHROP: I'd like to ask you some questions, if I can. You said that you have been a 32-year employee, yes? []

JILL McCONNELL: Correct, I'm sorry. []

SENATOR LATHROP: Okay. We can't make a record out of you nodding your head. []

JILL McCONNELL: I know. I think with all technology we ought to be able to, but... []

SENATOR LATHROP: Yeah. Not yet. What your position? You're still here now and you're looking forward to retirement, so I assume you're still working here. []

JILL McCONNELL: As yes...correct. []

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SENATOR LATHROP: That's also a yes. Okay. What's your position here? []

JILL McCONNELL: Speech pathologist. []

SENATOR LATHROP: And how many of the 32 years have you been speech pathologist? []

JILL McCONNELL: All. []

SENATOR LATHROP: Okay. You have...let me start with the letter that you wrote. You said you wrote a letter in 2003. You told us to whom that was written. Did you get any response to that letter? []

JILL McCONNELL: I got immediate response from the parents because I did include on my list I CCed the president of the Friends and Family of BSDC Association president. I got an immediate response from that group. []

SENATOR LATHROP: Did you get any response from anyone else? []

JILL McCONNELL: No. []

SENATOR LATHROP: You've told us everyone you sent that letter to. []

JILL McCONNELL: I think so, yup. []

SENATOR LATHROP: Okay. Senator Harms has asked this question of other witnesses, and I'm just going to ask you and maybe steal his question. But what if we're looking for not just the problem, but the solution. And you sound like you've spent some time thinking about this. And you've also directed some of your criticism at the management and you are a little vague, but maybe not so vague, about where you think

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the problem is. But why don't you tell us what your judgment is about what needs to be different. []

JILL McCONNELL: I believe that the solution lies in the right management. It's kind of hard because I don't think that's within your responsibility or anything you can do. But right now the process we used to have...do you mind if I go back to comparisons? []

SENATOR LATHROP: No, no because the one thing that we have heard is that this was an example of the way an institution like this should be run, and now it isn't. In fact, we have a lot of problems. And so someone that can give us a historical perspective on what happened to us between being the example of how to do it correctly to where we're at today, any insight would be appreciated. []

JILL McCONNELL: And I...just to preface this, I'm not saying that everything we did back then was good and there were no problems, and I don't mean to say that everything we do now is bad and it's nothing but. But back then after the lawsuit, Horacek v. the State of Nebraska, we started the process of building ourselves up to correct the situations that led to that. And what we ended up with was a place that had very firm policies and procedures. They weren't restrictive. They actually in a lot of ways were freeing because everybody did the basic things the same way. You could cross over living units or units and it was all regulated paperwork. And the ways you had to...the people you had to go through to get something done and the way, eventually, all the members of the IDT, interdisciplinary team, had to relate to each other or to work together for the benefit of each given individual. Every individual had an IDT made up not only of direct care staff, but also of the nurse, the speech path, the physical therapist, the teacher, and on and on. And for each person, those people were identified. In the process of the changes I mentioned, the convoluted outcome, being able...especially for someone like us, the professionals, I'll say, but I've always considered everyone here whether housekeeping or...we're all professionals, DT staff for heavens sakes. But the ways we were required to work together for an outcome

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were set. That doesn't mean that we didn't have a lot of freedom to create with each other or to try new things, but we didn't have to take time to worry about how certain things should be done. Now my observation is that we have policies and procedures, but they change daily. We've had QMRPs, qualified mental retardation professionals, and every week--and I can't tell you for how long, it has been a long time--every week the list of clients that this QMRP is responsible for changes. So every week you have to look at this list and say, well, who's that person's QMRP now? This is not efficient. It's not effective. It does not work not to have...to be able to make decisions, to disseminate the decisions, and to have everyone on the same page with those policy type daily care kind of things. It's like getting up in the morning and not knowing whether you're supposed to brush your teeth first. I mean, you know, we have certain set ways we go through our day. We can certainly change. But if we had to think about everyday how to do every thing, it would be a very wasted day and that's what it's like. If decisions are made, they don't get to where they need to be. When they get whipped to where they need to be, you can kind of count on the next day or the next week it's going to be different. []

SENATOR LATHROP: Okay. You mentioned that the interdisciplinary team approach, and you mention that as something that took place regularly in the past. Is that not the case now? []

JILL McCONNELL: It is supposed to be the way things are done, but it is because of the way people have been...I mean, the different positions, QMRPs, managers, the way things have changed so rapidly and so frequently, it is difficult to...decisions are made unilaterally sometimes by one individual. They're not appropriate sometimes. But no matter whether they are or not, no one is solely responsible for making a decision about an individual. It is supposed to be a group feedback input kind of thing. []

SENATOR LATHROP: So you'd sit down and talk about a particular individual who lives here and say, I think he needs this and I've notices this about him, and maybe we need

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to have speech pathology come in and do this with him, and that's missing. []

JILL McCONNELL: That is much more difficult and it not necessarily the common practice that it was. It is more difficult...if I don't know who the QMRP is today, first I have to search and see who that might be. That just does not lend itself to a coordinated approach for these individuals. []

SENATOR LATHROP: You provided this information in response to my question, and the question was what's different or what do we need to improve. Is that one example or is that it? []

JILL McCONNELL: That's one example of how difficult it is to know where you stand to find out what the decision making was on any given day. Decisions are made or not made and they never filter down. And if they...in the past, there was a structure so that decisions that were made about programming, which is active treatment. Each person who was part of the programming team. There were the unit directors, and they had the responsibility for a unit full of living units and of staff. There were the professional services, each education, OT, recreational, all of those, and that was it, the support services and the unit systems. They came out of that meeting and all of their staffs were apprised of all the decisions immediately in the same way so that the information that everyone got was the same, which led to somewhat of a stable consistent work environment. I...oh, I'm sorry, go ahead. []

SENATOR LATHROP: Well, that's so...are there any other observations about, you know, the way it used to be when it was done well versus the way it is today besides that? []

JILL McCONNELL: Yes. []

SENATOR LATHROP: I think you've made your point with respect to the continuity of

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care, the consistency, and the teamwork. []

JILL McCONNELL: I think maybe another important aspect is job satisfaction that it...and you've heard this before today. But I can happily remember DT staff--and you've heard from some of those today--who I absolutely...who were professionals. There are lots of those left, not as many as there used to be. And I don't think they get the rewards, and not monetary, that they got in terms of respect, being a very, very important part of the team and made to feel that way. I remember even before I had kids and after, I looked at BTs and I looked at this place and I said, if ever I needed a place for a person in my care it would be BSDC. And I was never ashamed, despite over the years there's always somebody who thinks institutions should close down. Well, what is community placement also? That's another way the state provides services for people who are appropriate to be in the community. But I would stand eyeball to eyeball with anyone over the years and argue and maintain that BSDC was a place that I was proud to work; and perhaps they might want to learn a little more about it before they made some off the wall thing about shutting everything down. But I must say that in the past three years I have been uneasy about the state of BSDC. And I will maintain that when you see the kind of things that have been going on and the steady...well, I first noted it, not noticed, but noted it in 2003 that has to be systemic. You can always have some incidence with employees. But if it is so widespread, if problems and issues, not with employees, but with problems are so widespread, it has to be systemic because if you aren't taking care of them one at a time and they get to this level of difficulty, then it goes beyond here. []

SENATOR LATHROP: Okay. I think that's all the questions I have, but I'm guessing there will be others. Senator Wallman. []

SENATOR WALLMAN: Thank you for coming here. And I know you worked here a long time and a good employee and I've always been proud of this place also. And you think this suspension thing is hurting morale. Has it helped the clients, you know, the

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residents any? []

JILL McCONNELL: It has hurt the morale. I know that when we had a temporary...one of the temporary fill-in CEOs, and this suspension business just blossomed, and his statement was, well, I don't know what they worry about. We just have to do this. I don't see why they're so upset about this. Well, because they're told...you know, you heard. []

SENATOR WALLMAN: Yeah. []

JILL McCONNELL: You go stay by the phone, don't do anything else, and when we're ready after 30 days or so, we'll call you. But I also know that in...I know CMS has changed, requirements have changed, and I may be wrong about this. But CMS defines abuse. They don't tell you what you have to do about it. My impression is that we have tied ourselves up so tightly by our policies, and I don't mean to say that you can just let it go, but we have never...this may be wrong, but again my impression is we haven't been cited for not attending to abuse. We've been cited for not following policies on abuse. We have made those policies so restrictive, and then not followed them that we've backed ourselves into a corner. It isn't that you don't have to pay attention to it, but you do have...I believe if you had a reasonable policy you would be all right. I mean, again with the abuse and neglect policy, these figures are not correct. But just like the QMRP list, there were several years when there were 27 revisions of it. First of all, how can you remember; and second of all, if you have that many revisions, you haven't gotten it right yet. []

SENATOR LATHROP: Senator Gay. []

SENATOR GAY: Thanks. Jill, I'm going to ask you on your experiences, Senator Wallman talked about those suspensions. What percent of the direct client staff do you think has faced a suspension or is in fear of a suspension? It seems to me that everybody coming up here, even long time employees has dealt with this issue. Is it just

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walking on pins and needles around here? []

JILL McCONNELL: Yeah. If you combine those who have been on suspension and those who are probably afraid of being on suspension, it would be 100 percent. []

SENATOR GAY: One hundred percent of the employees. []

JILL McCONNELL: If you include those who know the possibility and are afraid of it and those to whom it has happened, it would probable be 100 percent. Nothing's 100 percent, but I'll bet...I mean, you'd have to be in some other world not to be worried about it. []

SENATOR GAY: Well, concerned, but...okay. On another thing, you talked about the policies and I had talked about this earlier as well. Are these policies then...are these federal policies that CMS is making us do or is this things we have imposed upon ourselves as state? I mean and I know you're probably not an expert on every policy. But just your opinion, I guess. []

JILL McCONNELL: My impression is that the definition of "abuse" is federal, and certainly the requirement that something be done about it, but that would be all of our requirement. It is my belief that what we have set out selves to do about it is what's getting us in trouble. For instance, just for instance if you have a wart on your foot, do you cut it off or do you do something about that? We are so reactionary about abuse, neglect that we set ourselves up in many ways not to be able to follow our own policy when in fact we could certainly address the issue satisfactorily with more rational policies and still be okay with the feds, I believe. []

SENATOR GAY: Okay. You talked about the abuse and neglect policy. I want to talk about all policies from showing up to work to whatever. We all know government. We've added, every year, more and more rules, regulations, policies, whatever. But I mean are

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these things that we're, as a state, saying we need to do or is it federal? And I'm not just talking about abuse policies. That's a very important topic, I know. But just, you know, when you walk in there's a policy manual everyone has. Do they go from here to here because of the federal government or because we've done this to ourselves? []

JILL McCONNELL: I think...we used to have, okay, lots of policies. They were...okay. Now, I'm trying to think what I want to say. They were so reasonable and so rational that you knew from day-to-day. You could keep yourself out of trouble from day-to-day because there wasn't anything that was shot out there today. This is the new policy, start it. And any policy that came about new or was changed it was within this...you know, it wasn't federally mandated. It was mandated by rational...by the need to have a standardized dependable work environment. So the things that I'm thinking now are not mandated, that I'm thinking in my head are not mandated by the federal government; they're mandated by a reasonable workplace, especially a workplace where such important work is done. So if a policy was going to be changed, it was changed with the input of all interested or involved parties. And out of those informed people came a new policy that was communicated to everyone. []

SENATOR GAY: So you went off the experience, I guess. And thank you very much for that. I guess that's the question I will ask later of upper management then because it is an interest to me why, you know, many time they're forced to change policies because it's topped down federal government. But we'll deal with that later. Thank you very much. []

SENATOR LATHROP: I think that's it. Thank you for your testimony and for coming down here and talking to us in spite of the fact that it makes you nervous. []

JILL McCONNELL: You can see why. []

SENATOR LATHROP: Thank you. []

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JILL McCONNELL: Okay. []

KAREN GIRCH: (Exhibits 3-4) And I volunteer. I do have copies of what I'll mostly say for each of you. []

SENATOR LATHROP: We'll have you sit where the mic can pick up what you're saying, and then give us your name. []

KAREN GIRCH: Hi. I did provide testimony to each of the senators here. My name is Karen Girch. I'm an employee at BSDC. I started here in 1975 working as a summer teacher and...no, I started in 1975 as teaching staff while I was in college. I was care staff through my college career in order to pay for college. In 1979 in May, I started as a summer teacher here. That fall, I then took a full-time teaching position, and currently I'm in a human services treatment specialist position that's essentially an adult educator. So I'm basically doing what I was doing when I started work. BSDC is an educational entity. Our funding requires that the individuals who live here have learning opportunities every day, all the time. In my position, most of usual case load is eight individuals. So if I were to spend my entire eight hours that I'm here everyday with my eight individuals, I could devote to them an hour a day. Five days a week they would have an hour a day of being taught. As a person that's most responsible for teaching and educating those individuals that live here, I know that the standards require we provide continuous education. So the greater part of my job is to teach people how to teach and to provide the procedures for those folks. I communicate those to the team based on what that team has decided for that individual that's important for them. I see frontline staff working with individuals everyday. That's how I know what they need to be taught is because those staff that are with the individuals eight hours a day, they know what...though the individuals that know what they need. There are, however, a number of staff here at BSDC who don't have the time or responsibility to directly spend with the individuals, and to me that's something that's very wrong with BSDC. When Hugh Sage

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was here...you all know that time. We were that model facility. One of the suggestions I took to him during the '80s sometime, I don't remember exactly when it was instituted, but he approved and developed a voluntary program that allowed employees in any position here at BSDC to spend up to two hours every two weeks of paid time with an individual that they chose to work with and spend with, be their friend, do normal things that people would do. And many people have developed long lasting relationships because of that. Lots of people go in...they may go from a direct care position to another position where they don't have those direct responsibilities. But we still wanted to make it so that they could spend time and remain friends with people they knew. I worked on trying to get this program more of a mandatory program for people. I fully believe that everyone who works here needs to know and spend time with the people who live here. They're why we're here. I'm not here to push paper. I'm here for the people that live here, and I wish everyone else were too. my most recent attempt at this evolved through a work group. I presented our proposal to the leadership team, and it happened to be last Halloween. That's why I remember it is because it was Halloween. A member of that group made the comment, if I'm out with clients I might get suspended. That absolutely appalled me that those people making those policy decisions had that attitude. John Wyvill happened to be at the happened to be at the meeting. He gave us a little pep talk at the time. I didn't know whether that pep talk was directed at maybe one person in the room. I didn't think it was. He didn't make it seem that way. But he said some things that we all needed to hear. The work group that I was on, trying to get that program so that it was more formal, continued for a while, but so much resistance kept coming. So many regulators came in and said you need to this by next week, you need this done and this done. Ron, our current CEO, has made it very clear to leadership that they need to be out. He has said that. I see some staff who are listening to him and following that direction, I see others who aren't. Just so you know who I am and where I come from, I do a number of things at BSDC. I'm cochair of the local safety committee. I'm cochair of the Department of Health and Human Services Suggestion Committee. I'm member of several committees here on campus, family style dining, labor management. I teach and mentor the people who are new in my position to teach

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them how to do the things they need to do in their position. I'm a member of the statewide safety committee. I'm also a steward. I'm a member of the bargaining team that bargains and negotiates the wages and other benefits and rules and regs for the union. I'm on the board of directors of NAPE/AFSCME. I'm a member of Friends and Family and MRAN. So I've got that aspect, too, and that knowledge. Unfortunately there are a number of people at BSDC that have talked to me in the last few weeks about being afraid to come talk to you today. They're afraid of repercussions. They're afraid they will be targeted. I did give Senator Wallman a statement, and you are all welcome to it, from an employee that did not wish to disclose their name. When they gave me the statement, I asked them if they would sign it, and they chose not to, but they were willing to write my name on the statement as if you have questions for them and you need to contact them, you can do that through me. And if you have any questions for my now or later, feel free. []

SENATOR LATHROP: All right. We'll see if there's questions. I don't think so. []

KAREN GIRCH: Okay. []

SENATOR LATHROP: Very helpful Thank you. []

PAM SPIER-EDMOND: Good afternoon. I'm Pam Spier-Edmond, S-p-i-e-r-E-d-m-o-n-d. I have several things that I would like say. I started here in 1987, two days after I quite college thinking that I wanted to work for a living. Within a day, I was like why did I quite college. But I was lucky enough to have several staff that told me, give it six months, you'll love it, and then go back to school if you want to. Six months came, two years came, and I left in 2001 to return to college because I wanted to move up. And I worked in a group home and I remembered distinctly saying, when I returned to BSDC after working in that group home, to--I think it was the area director at the time--unit director, I told him that I have never felt more secure and safe in a facility as I did working at the state home. I loved our training. I thought we trained our staff very well. And when I

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worked at the group home I was told you're very well trained. And so that's...I mean, the safeness was there in the institution. I don't even like using that word, so. But on the flip side, I liked working in a group home. It's just the resources that if there is an emergency behavioral incident or anything, it was me and three other staff of four behaviorally disordered borderline intellectual adolescents with severe violent behaviors. Of course after 12 clients, that can potentially harm you, and in fact brought a gun into that facility. I was scared. So I came back here. I eventually received my four-year degree and I came back to work at BSDC because I have the opportunity to be a part of several great teams. I mean we functioned, we go things done. I'm still part of several good teams. And as an assistant administrator, I have several areas that need more help at time than others. And my area is the behavioral disorder area classified. I like what it do. I like where I work. I like community providers. I like community providers. I like BSDC. I think there's a place for both. I like the fact that our clients can choose one or the other. I have several individuals that do not want to be in the community. They don't want to go no where near it, they've been there, done that, and they feel safe here. I also worked in OTIS program, so I have been in the community in the community-based homes. I've also had those people tell me, how can you help us? We need help. They're out in a house and they have an individual that's going off. The only thing that they know they can do is call the cops. They're staffing issue are just as bad as our. I'm not saying that our staff...and we have staffing issues. But again I like the fact that our individuals can choose where they want to live and they can work on their problems while they're here, and if so they're ready to leave, then they can go. I would like address...Karen had brought this up and several other people had brought this up, support to our staff. A I said, I think we have some of the best training here. I think there's always room for improvement definitely. If you think you know it all, you're wrong. And I've said that to many people. Everyday here is a new learning experience for me and, you know, I learn from the staff, I learn from the clients, I learn from the great people that I work with, the people that help me through the day. I like to look at this place as we're continuing to move on. I don't want to live in the negative here, and I've been accused of being too happy at times or being too optimistic. Pam,

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don't you know that we're going to go under? Why do you keep trying to fight? Because I believe in BSDC, that's why I will always fight. Optimism? Absolutely. We have to look at what we do now. It did not...the problems at BSDC, and I agree, did not happen overnight and it will not be fixed overnight. Absolutely. I mean, this has been, you know, several years in the making. You know, CMS, they flip those federal guidelines on us, and you know the responses, the arguments that we have had with CMS...I was there. I have heard them. We tried to argue. We tried to say, well, we're doing this. We tried the different degrees of abuse and that's where we, you know, it came up--abuse is abuse. Let me see, just (inaudible). Again, I believe in both the community and the institution. I will give you an example of why I believe in the institution and it happened last night at 7:00. I was working with Ron, our CEO, on a home that was having some major issues yesterday, and issues is actually an understatement--violent behaviors. We had a staff that was bitten and blood drawn. I mean, he was bleeding. This staff will also need cosmetic surgery for his bites that he has received from one individual. So this home is having some major issues. I'm working with Ron. Ron's being called by the team. We're deciding what we can do. We're trying to implement some things in this home. Great group of people, newly formed team, but they're working, they keep coming back to work everyday. I call, I see if things are going okay. They are. At that time around 7:00, I see three staff walking, following a client who is in a major violent episode. He is throwing whatever he can find at these staff. They charge. I'm walking up to the scene thinking I'm going to help out, and this individual bulldozes through me like I'm a wet noodle and throws me into a metal pole and throws me down. I get back up. I didn't notice that my right knee was lacerated. He runs out into the street. He is threatening to get us all suspended. He knows how to do it. He will do it. He runs and he grabs onto a pole and he is saying I'm going to hurt myself and I'm going to say you did it to me. He ends up on a deck throwing rod iron chairs at the staff, and we eventually had to put him into restraints. I was just in a meeting where restraint usage is down, but the number of staff injuries are coming up. This is sometimes can be a daily occurrence for these staff. I still hadn't really notices what happened to my knee, and I ended up in the emergency room with sutures. I have a bone bruise, and those staff did an excellent job. They did

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what they needed to do. They attempted to back out. He would swing at them. On my direction, they attempted to back out. He attempted a head butt. He attempted to bite. And they were worried. They're still worried. I'm worried. He threatened to suspend me. But they're here again today, these staff are coming back today. What are we trying to do within this home? We're trying to support them through training. Unfortunately staffing is a major issue, but there's some very dedicated and devoted staff in this home. And I, you know, as I called them at 10:00 last night, I told them that I appreciate everything they do. To touch on professional staff support, I also am in the living unit pool, and I do anything...because I started out as staff, and I've been in different roles out here. I do anything that they ask me to do. I also work with them and train with them and role model. They train me, they keep me going. And so I work with the unit pool on Saturdays and Sundays usually. And I will...you know, I'm willing to support anything that they do because I know that the staff out here tried their best. And we have added a lot, a lot of things to them, so much so in a sense that I don't know how they do it. Our supervision policy typists ties us up a little bit, but it's a needed policy. We need to know what our clients are doing. We have been working on it to try to not be so restrictive. But sitting in some of the meetings with the federal government, you know, they've tied us, they've tied our hands. And that's really hard to communicate that, and the unknowing is always very disheartening out here. You know, the confidentiality...you know, I wish I could tell people what's going on, but I can't. It's a confidentiality issue. You know, I do take the time to talk to people when they come to my office. I'm not really in my office. Many times I usually go hunt them down. But professional support, I believe that I'm there. I believe that my staff know that I support them at all times. Again, I think there's several things that we can do. But this problem didn't happen overnight and it's going to take a while to make a change, and we need a cultural change. We need to change some of the ways that we do things. We know that and I believe that we need to empower the staff more to feel confident in their jobs because they do not. Their skills are lacking because I don't think they have felt that they can use their skills. And that is something I seen last night. If you're so scared to intervene with somebody because it's a safety issue, would we let people in the community throw rod chairs at other people?

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No. But if you're so scared to get suspended, then you're not going to intervene, and sometimes...I know that's what's happening right now. So that's all I have to say. Any questions? []

SENATOR LATHROP: Very good. Thank you, Pam. Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Thank you for your testimony, Pam. You've been here quite a while already. Do you think things are improving? Are things better as far as staff being in management now as it were six months ago? []

PAM SPIER-EDMOND: I look at cover sheets every morning. In fact, I'm very proud of looking at my cover sheets because I usually know where the staff are, who stayed over, who volunteered to stay over to help us out. So as I've seen those cover sheets, I see less and less mandatory overtime. And so yeah, I do believe that in staffing and some of those issues, yeah, I do believe some of those things are improving. Management, yes, I do believe that we're supporting more, there's a feeling like we're being supported more in some of the decisions that are made. I have a great group of people that I turn to with some of those issues. If an issue arises, I call and i, you know, kind of throw things past people and see, you know, can we do this, should we do this, how's this going to affect the way we do things daily. So yes, since six months ago, absolutely I think things are better. That's my opinion. []

SENATOR STUTHMAN: So in other words, you know, we've heard a lot about communications, people are just scared to talk or anything like that. Do you think that's getting better? []

PAM SPIER-EDMOND: The people that I interact with are not at all scared to tell me what's going on or ask me what's going on. In fact, I'm very proud of the people that I work with especially the DT staff that are willing to come forward and just tell me, I don't agree with this, I don't like this. I actually meet with the DT3's, which are the leads on

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the home, every two weeks. We had a great discussion this last Tuesday on supervision and seniority and lead staff, who should be in charge and, you know, they really had a lot of valid, very valid points and we worked with them on that. They taught me some things. []

SENATOR STUTHMAN: Okay. Thank you very much. []

SENATOR LATHROP: Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. Thank you for coming, Pam. I appreciate what you do. I'm sorry about your injuries. But as far as the residents here, have you seen more violence or what...do you have the authority to dispel somebody or move somebody out? []

PAM SPIER-EDMOND: We're a teaching facility, so that's out job to teach people. We have at times worked with other facilities in attempting to support teams and the individual in trying to work them through behavioral issues. There are different places we can go to, but not many. You know, that's out job here is to teach people how to control their anger. []

SENATOR LATHROP: Senator Gay. []

SENATOR GAY: Pam, you've been in this field for a while. We know, for instance, the negatives and you got to talk about those to get them out and find out where we're going wrong. What is the measurement though? How do you measure...I heard from earlier somebody that came here that said I saw the good times Jill talked about. I've been here, I've seen when we were great, and now you know I feel bad. What do you measure against? What is the ideal measurement out there in your industry that says we want to be here or we may be here and we want to be here? What's your goals here? You're in management. I mean... []

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PAM SPIER-EDMOND: My personal goal... []

SENATOR GAY: No, I want to know what's the facility's...what are we reaching for here when they talk to you about...management talks to you, what are we going...where are we going right now, I guess? What are we shooting for here? []

PAM SPIER-EDMOND: I think right now we're shooting for a standard of excellence in supporting individuals and making choices for their lives and in all aspects. You know, that's our vision is to teach and that's where we're going. I think that we can get there too. I mean, how to measure that, are people happy? Are the clients happy? Are the staff happy? You know, in a perfect world, everybody could be happy. But you know, do people want to come to work and you and see if people want to come to work by the decreased amount of sick time. We had an average of 20 people calling in a day on all three shifts. When you're already at bare minimum staffing and then 20 people call in, wow, that's a big punch. You know, and so it kind of gets back to are things getting better, and you can see the things getting better by the decreased number of sick time. Even you know...are people passing the programs, our BMP programs? You can see that through decreased restraint usage. I know of several individuals in my area that have graduated their BMPs. Something's going right. You know, the staff are doing something good. Those teams are in there doing some good work. And you've got to see that and you've got to celebrate the positives. Yes, people are calling in. Yes, people are being (inaudible). But you know on an average of 20 people calling in every day and now I'm not sure if that's the same number, but from the cover sheets I don't see that. So I measure things by what I can see and, you know, what power in my managers interact with me and tell me what's going on on the living unit daily and how the QMRPs are telling me that they're individuals are graduating in their programs. You know, some people have never thought that they would get there. They did. That's a measurement tool that we use. I don't know if that answered your question the right way. []

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SENATOR GAY: Well, it's a tough one to answer. But I just wondered, you know, sometimes we face performance on these measurements, and I just wondered if some of them would pop into your head and said we're doing this, this, and this because that's our goal. That's what we're all striving for, and... []

PAM SPIER-EDMOND: We're adjusting our sick time through some different guidelines hoping that that will provide the boundaries and, you know, set some standards within the home and within your own person. People work better knowing boundaries. People work better having limits or not necessarily limits, but setting guidelines. If I can come in everyday and not do anything, I'll probably come in everyday and not do anything if nothing's expected of me. []

SENATOR GAY: Well, you wouldn't do that. You sound like a very positive... []

PAM SPIER-EDMOND: No, I would not. []

SENATOR GAY: ...very positive employee. []

PAM SPIER-EDMOND: I'm very passionate about what I do. []

SENATOR GAY: You are, I could tell. []

PAM SPIER-EDMOND: And I've very passionate about the field that I work in. []

SENATOR GAY: I could tell. That's awesome. []

SENATOR LATHROP: I think that's it. []

PAM SPIER-EDMOND: Okay. Thank you. []

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SENATOR LATHROP: Thanks for your testimony. []

SHELLY WILES: I wasn't planning on speaking today, but...my name is Shelly Wiles. []

SENATOR LATHROP: Can you spell your last name, Shelly. []

SHELLY WILES: W-i-l-e-s. I am a DT staff out here. I just spent the last 15 months on the behavior unit that Pam just got done talking about. I've... []

SENATOR HARMS: Shelly, would you speak up please? []

SHELLY WILES: Yes, yes. I spent the last 15 months on the behavior unit that Pam just got done speaking about. I've never been suspended, no allegations, never been hurt on that unit. I've tried to explain to managers how to fix that unit. They don't want to listen. I'm no longer on that unit. I just transferred off because I feel that is was hopeless to fix it. I care a whole lot about the clients out here. And there is a solution to fixing BSDC. Unfortunately I don't know if we have the staff or the resources to do so. I would like to say yes, but until people start listening and not just listening but doing something about what goes on out here, it won't be fixed. I do know how to fix it, but this isn't the time or the place in front of everybody to discuss the changes that need to be made. About a year ago, I brought up what needed to be done, and in return I have been retaliated on. I have been harassed by coworkers, by managers, by A building, by payroll, by a lot of people. I'm not from this town. I'm not related to anybody. And from what I see, nobody wants to change anything, nobody wants to be held responsible for anything, and that's unfortunate because I care a lot about these clients. I love these clients. I'd also like to say that John Wyvill has made a huge difference in the way BSDC is now operating. If we could have 50 more of him, we would be on easy street. Unfortunately we still have to go through John Wyvill to get anything done around here. We can't just go to managers and, you know, say hey, this is what needs to be done.

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You know, they'll listen, and then they'll just pat you on your head and send you on your way. You know, they don't...they lie, you know. I've been lied to so many times by managers out here, and I think that's the worst, you know. As a DT staff, we can take it when they say, no, sorry, we can't do it this way. But when they sit there and drag things on and on, you know, it makes DT staff very hard at heart, very resentful. And in return, I think a lot of times I think clients get the brunt of the way DT staff are treated out here. I guess that's all I have to say. But I do thank you for appointing John Wyvill to helping out BSDC. []

SENATOR LATHROP: You may be giving the wrong people credit for that one, but...(laugh) []

SHELLY WILES: Okay. Well, whoever appointed John Wyvill, he has... []

SENATOR LATHROP: We have heard people say nice things about John and we're glad that that's working out well. And Shelly, thanks for coming down. I would suggest to you, and maybe you're not comfortable offering your ideas, but this is the time to do it, this is the place to do it if you're comfortable with that and if you care to. We're not here to put you on the spot, and I... []

SHELLY WILES: Oh, it's not the matter of caring. It's the matter of my job, and it's not just the job because I can get a job anywhere, I can get a paycheck anywhere. It's losing my clients. If I get fired from this place, I will not longer see my clients, and one of them I have known for like 23 years. I mean, he...you know, there's a lot of history there. And for that to be ripped away would be unimaginable to me, if that makes any sense. That is why, yes, I want to stay here. I want to fix this place. But I'm not willing to lose my job because if I lose my job, I will lose my clients. []

SENATOR LATHROP: Senator Harms. []

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SENATOR HARMS: Thank you, Senator Lathrop. Shelly, have you...you talked about being harassed and treated poorly, have you filed any kind formal complaints on any of these? Have you gone to your supervisor and complained? []

SHELLY WILES: My first one was filed about 16 months ago, and life has not been pretty since. So no, not formally. []

SENATOR HARMS: So have you... []

SHELLY WILES: I tried one other time about the payroll issue and the union did not accept the grievance that I had written out. They didn't want to have anything to do with it because of the people that it concerned. []

SENATOR HARMS: Going back to your...the one that you recently filed, did you file that with your supervisor or... []

SHELLY WILES: The union steward. []

SENATOR HARMS: No, not the union steward. The other one that you mentioned earlier. You had filed a complaint about...oh, I think I asked the question. Maybe I'm not hearing you. The question about whether you have taken on the issue about being mistreated, harassed, that sort of stuff, and you did say you, not formally, but you did visit with your manager, is that correct? []

SHELLY WILES: Oh, yeah. They are well aware of what is going on. []

SENATOR HARMS: Okay. Have you ever gotten a reply to any of that in any form about how to correct that or anybody getting between the issues? []

SHELLY WILES: I corrected the situation. I transferred off of 108. I feel like I'm in a

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safer position now, a safer area. []

SENATOR HARMS: The question is you really shouldn't have to do that. Did your supervisor in any form or manner make any attempt to correct that? []

SHELLY WILES: No. []

SENATOR HARMS: Thank you. []

SHELLY WILES: Thank you. []

SENATOR LATHROP: Thank you very much for coming down. []

TED BURI: Good afternoon, Mr. Chairman, lady, gentlemen. My name is Ted Buri B-u-r-i. I am a contract administrator with NAPE/AFSCME located in Lincoln. I have worked with NAPE here for about six and a half years. I'm in my 32nd year doing essentially the same types of functions. The prime focus of my duties assigned now involve providing support to our leadership and stewards in the field, including BSDC, processing and handling grievances at the upper level of the grievance procedure, and conducting administrative hearings, personnel over hearings and arbitrations, and some other duties that are not necessarily (inaudible) to what we're doing here today. After that last testimony, I feel kind of like I'm following George Carlin and George Burns. (Laugh) I had prepared a reasonably lengthy statement to go through today, and I've decided to scrap that because most of the issues that I was going to address have been addressed very clearly, very forcefully, and I think in a much better way than someone from the outside could relate to you. I think you hear the emotions and you hear, you know, the personal effects of those issues on people and, you know, I don't have to live with that every day. What I would like to do is I noticed that there were some questions and issues that I thought it might be helpful to clarify or amplify upon. And that's what I'd like to do just very briefly, and if there are any questions that I can help you with, I'd be

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happy to do that. Some of the...I lost a piece of paper here somewhere, some of the issues that I think could be revisited just briefly are there were issues related to the subject of investigations. And I believe it's been made clear that nearly all the references made today were to investigatory suspensions. When we talk about suspensions, there are investigatory suspensions, there are also disciplinary suspensions where the employee is suspended without pay as a part of the disciplinary action. One of the questions was does the employee have any recourse or any upheaval to those investigatory suspensions. And the answer to that question is yes. An investigatory suspension is nonetheless a suspension precedent that that issue has been clarified through the procedure. An employee does have the right to grieve an investigatory suspension. Now in reality, that doesn't change much. They're still going to be sitting at home. They're going to be sitting at home without pay for the first six days, after which it automatically converts to suspension with pay. And You've heard some of the examples today of the amount of time that it takes to complete this investigatory process. And so what happens is you have people sitting out there for an inordinate amount of time being paid to watch Oprah or read books. Now they're admonished to remain available to return to work. They basically remain readily accessible. For the most part I think people comply with that, some don't. But you know, it becomes a bad business practice. You know, why, if there were any reasonable alternative, why would we want to pay people to sit at home and do nothing? It makes not sense. So in regard to this issue of the investigatory suspensions. I personally have some issues with the amount of time it takes. One of the gentlemen said that we have to be thorough, and that's true. They do have to be thorough. But what happens is it seems like there's very little effort to do an immediate review, my personal opinion. An event occurs, an employee is accused of some form of abuse or neglect. There is a very cursory determination made. If the agency is following their own policy, they immediately remove that employee from the work environment, rightly or wrongly. There's a very rescreening process and the employee is sent home. Most of the people who testified here today that were on suspension will tell you that they had very little, if any, input, you know, before that process occurs. Okay. Now if you're going to take 45 or 60 days

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or even 15 days to investigate the situation, you know, one of the key components is you need to talk to that employee. That employee needs to have their opportunity, somebody said earlier, to confront their accuser. I don't necessarily know that you bring the person in and then they have a face-to-face. But that person has the right to know specifically what they're accused of, why they're being accused, you know, who are the witnesses, what was said, what was done. That very rarely happens. I won't say never, but it's rare. That person is called in. They're sent home. Their questions are not fully answered. They lose six days pay, and then they sit around and do whatever they're going to do with pay for a couple of more weeks. Now are the people that are doing the investigations here, are they doing their best? Are they trying to be expeditious? I'm sure they are. But most of the people that are doing that are not necessarily trained investigators. Many of them, it's a skill many that many of them have to acquire as they go along. And I don't mean to be negative of them, but the result of the process is that people are out of the workplace. Continuity of care is disrupted. The workplace is disrupted. Everybody and their grandmother knows what's going on. We talk about confidentiality. Confidentiality is a joke. Everyone knows what's going on here on a case-by-case basis. And I'm exaggerating only slightly for a fact. So they go home. Their families are disrupted. There's a question in the family's mind and the kids and the spouse. You know, what did you do? Did you do something? You know, there's always a lingering doubt there. It gets out into the neighborhood. So that person is damaged. You know, even if they're brought back and completely exonerated, you can't go back and take that back. Okay. Now is the agency required, obligated to investigate any allegation of abuse and neglect? Absolutely. I'll repeat what several people have said today. I'll characterize this as my own personal opinion, but I don't think anybody here would disagree, and that is if an individual conducts, engages in a willful, knowing act of abuse and neglect, then they need to be gone, no questions asked. Okay. It's everything between that person saying "freaking" or raising their voice, it's between there and the actual physical abuse or the deliberate embarrassment of a client through verbal abuse. There's so many different things that range between those two points. You've heard...I won't go down that rabbit trail, you've heard over and over again today

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the fact that there's not way, at least no way that's being utilized, to try to sort through those issues to apply some common sense to that specific issue and try to find the appropriate level of interaction and corrective action that needs to take place. It's a one size fits all with very, very few exceptions. You've heard a couple of examples today of the types of things that bring about that automatic suspension. Just to give you a couple of examples: Staff are on duty. They're all doing their assigned duties. They've checking on clients. They've changing clients. They're doing laundry. They're doing paperwork. And while they're doing that, you know, with no deliberate actions on any of the staff part, a client gets out of the area where they're supposed to be. And they walk around and they get into another client area or they're in an area where they're out of sight, where there's potential for client-on-client harm or potential for the client to harm themselves and it's inadvertent. It's a momentary oversight while people are doing the best that they can. You're suspended. That's abuse and neglect. There's so many things going through my head I tend to freeze up. But an employee in the institutions...some of the 24-hour institutions are more formally structured in terms of their patient checks. But in any of these facilities there are regularly scheduled times when you're not in direct one-on-one interaction with the client when you have to check on those clients to make sure that they're okay, to make sure that they're breathing. Sometimes that's even more critical at night because they're in their rooms. You have to go and physically check on them. And there's a record kept of those. Okay. Well, maybe sometimes in the nature of the work the amount of duties that have to be done during that shift, client interactions have to be taken during that shift, well, maybe you forget to mark down your checks on that client to make the appropriate record. You know, that has been interpreted as neglect. If you go back and say, oh, gee, I forgot and you go back and show later that you made those checks at a certain time, some people describe that as falsification. You know, there are people who do very stressful work who make hopefully one-time errors, you know, errors that do not result in harm to the patient or harm to the mission, but they're neglect and abuse. Why are they considered neglect and abuse? You've heard a number of people today talk about the relationship between CMS and the agency and CMS and this institution. I don't think anybody would

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disagree with the importance of the oversight role that's provided by CMS and JCAHO. This committee now is a part of that mix. The client advocacy groups, they all have an appropriate role and they all help to ensure the ongoing welfare of the clients. Okay. And that's good. But there has to be some point at which management, whether it's at BSDC or Lincoln Regional Center or wherever it might be, has the right to carry out that authority that they have at the discretion of the Legislature and the Governor and the statutes to do their job, to make appropriate decisions in the day-to-day operations of their facility. What's happened is the directives, the fear factor brought about by the continuing thorough oversight by particularly CMS has created an environment where everyone from the agency heads on down are having to live everyday with this threat of losing \$28-29 million. Okay. Would that really happen? I hope not. Could it happen? Certainly it could. I think that the state's reaction would have to be pretty drastic for that to happen. But the other thing that's happened, not only is that a potentially real threat, there are individuals in the state who have latched onto the that threat, have used it for their own purposes. It's become a very handy foil for people to intimidate and threaten and harass people with whom they have problems. Every time...and I'm on the top end of this process, so all the grievances come up, complaints and appeals, and every time without fail the one thing that you hear in every hearing is, well, we didn't have any choice. HHS doesn't have any choice. We had to do this because if we don't do it, CMS is going to take our money away. Well, you know, I hope they...I often accuse them of not really believing that. I hope they don't really believe that. Okay. I hope that I'm partially correct and that part of that is just using that threat as a foil to, in their minds, get to the point that need to get to in terms of employee control and corrective action. I hope to me the only immediate hope of making any short-term major changes, not just in this institution...and by the way, personal opinion, there are bigger fish to fry in this agency than BSDC. That's my personal opinion. But the only immediate hope I can see is if the state, the state meaning the Governor, the Legislature, the agency, DOCS is a part of that mix 24-hour facilities, is to find a way to have CMS and JCAHO, that advocacy groups, HHS management, BSDC management, the union, nonrepresented employees have people sit down at the table and find some way to do what was talked

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about earlier a number of times, and find a way to separate wilful conscience abuse from inadvertent errors or minor errors that have not resulted in harm to patients. That's just got to happen because if that doesn't happen, nothing's going to change. I'd like to just very briefly compliment Mr. Wyvill too. Among a lot of other qualities that he has, Mr. Wyvill is a good soldier. Okay. When we complain to the agency about the overreaction to the threats from CMS, Mr. Wyvill doesn't hide from the issues. He takes the responsibility. He says, I'm the director, I make those decision. Okay. And I believe that John is a person of good faith. I sincerely believe that. Not just John and I don't mean to criticize by reference other administrators. Chris is still sitting back there I think. She's a person of good will and good faith, but that's not helping much. Okay. And I think...and I really believe the only way it's going to be resolved is through legislative...what's called an interaction with the Governor. There's just got to be a way to make the feds want to sit down and rationally discuss this thing. And I believe if you get to the table with CMS, CMS will say essentially, why are we here? One of the ladies said earlier, we just want you to enforce your own policies. If you don't like your policies, change them. I really think that's a part of what you're going to hear. And so what I think is happening is an overreaction in one part. An overreaction to the tone of the criticism from CMS, and on the other hand and opportunity to use that pressure for people's own devices. Okay. Are things getting better here? I would say it's somewhat better. And I'll say again, this is not the biggest boil on our backside. But again, what of the other issues, mandatory overtime, is it getting better? From what I understand, it is getting better. But we have to remember if you look back at this and all the other facilities, it tends to be cyclical. And some of the things that can cause mandatory overtime to drop for a period of time and then come back is money. You know, when we have money to spend on hiring temp staff and pool staff and bringing them in, that can ease your mandatory overtime figures. And so hopefully this is not just a temporary dip in the process. Hopefully it's permanent and hopefully as they continue to fill vacancies, it'll get better still. Filling of vacant positions: I'm afraid that if you filled every vacant position that you have here at this institution today, you're still going to have problems because...and again, my personal opinion, I'm not a budget expert. But I think most

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people would agree with me that certainly over the last eight to ten years staffing at this and other institutions, what that means is the minimum number of people that we can get by with that we can afford to pay is not full staffing. Full staffing is a staffing--Mike said it this morning--full staffing is a staffing that allows you to be prepared in advance for a reasonable number of illnesses or reasonable number of injuries, for vacation time, for whatever else might come up. And it doesn't mean that you need to have an overabundance of staff. But full staffing means exactly that, you have some cushion. And so when most people say staffing, they're really talking about bare bones staffing. I think those are...I think I've recalled all the things that I had written down on the piece of paper that I managed to misplace. I'd be happy to help with any questions that I can. []

SENATOR LATHROP: All right. Thanks, Ted. Looks like we have less questions as the day goes on (laughter). []

TED BURI: I think you have prudent committee members. []

SENATOR LATHROP: That might be the case, that might be the case. []

SANDY ZABOKRTSKY: Hi. I'm Sandy Zabokrtsky. I'm a parent of a handicapped adult. I'm the home manager on 106/108, and I used to be the team leader on 406, so I kind of got all sides of Area 1 (inaudible) behavior. Just have a couple of quick things to say. I suffer from a lot of frustration. My frustration is as a parent. I won't put my son in community services. I will not subject him to the quality of staff that I have seen there, that I have worked there because I've been an employer there. I won't put him there. I've met people that I used to work with that were clients in OMNI that were employees at the facility. Excuse me. That's putting my son at risk. I realize he's not...he's mildly retarded. He's got a plethora of other things going on with him, would only get a few hours. But I'm not going to put him there. They're not screening their staff correctly. They're not training their staff correctly. I've seen the quality of training that they give to their staff. It's atrocious. It's unforgiveable. And these people are supposed to be then

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taking care of the handicapped. It's not happening. It's putting individuals at danger. I have a daughter who works in community services in Iowa. I know that she got a lot more training than what they do in Nebraska, and it's really sad. We heard a lot about suspension, and I kind of can float among all of them because I'm one of the few managements that have managed to butt heads with enough behavior individuals that have had false allegations put against her. It is frustrating. One of the most frustrating things is we're here to be a therapeutic community. We're here to serve these individuals that have not learned...that have got themselves put here because of their inability to deal with their anger, with their frustrations. And the way they handled it is by very, very criminal means, very, very dangerous means. I've had two surgeries courtesy of individuals here. We by responding as quickly and as inside the box is what we are doing now to the false allegations. We're impeding any kind of therapeutic process for these individuals. We need to think outside the box, but we need support to do that because I've also been on the grilling side of CMS. I've also been in that area and watched how they've tried to catch and they've tried to find mistakes. It's none of it's pretty and none of it's easy. But it's a wide variety and it's not just at BSDC. That's kind of my real quick spiel. I'm going to stick to my ten minutes (laugh). Now what question? []

SENATOR LATHROP: You might just be under it (laughter) which is fine. We encourage that too. []

SANDY ZABOKRTSKY: Hey, I've been accused of being very long winded and I promised everybody I'd be very short winded this time. []

SENATOR LATHROP: Thank you and I'm going to ask you just a couple of questions... []

SANDY ZABOKRTSKY: Sure, no problem. []

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SENATOR LATHROP: ...to help clarify and put in perspective. You said you have a son that has mild disabilities. []

SANDY ZABOKRTSKY: No, he has major disabilities, just mildly retarded. []

SENATOR LATHROP: Okay. []

SANDY ZABOKRTSKY: He's got XY... []

SENATOR LATHROP: Is he here at Beatrice? []

SANDY ZABOKRTSKY: ...no, he is not. He's at home. We are providing services for him and attempting to find a job for him that he'll be happy with. []

SENATOR LATHROP: Okay. And how long have you worked there? []

SANDY ZABOKRTSKY: How long have I worked here or how long have I worked in the field? I've worked here I think five years this time. I've worked here several years about five years previous, had to quit because I had to take care of a husband that got struck by lightning. And then...I don't know why I said that, and then I've come back. I've been in the field since I'm 19 and I'm 55, as much as I don't like to admit it. []

SENATOR LATHROP: But didn't you notice nobody here asked you that, too.
(Laughter) []

SANDY ZABOKRTSKY: I don't care. And you're not allowed, it's against the rules. I learned that. []

SENATOR LATHROP: Well, no politician would. All right. []

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SANDY ZABOKRTSKY: But yeah, I've been in the field since I was 19 years old. I came up through it, although I have the degrees, I did come up through it through the hard knocks. So I've been from the beginning to the end. []

SENATOR LATHROP: All right. Thank you. []

SANDY ZABOKRTSKY: And whatever, questions? []

SENATOR LATHROP: I don't see any. []

SANDY ZABOKRTSKY: Okay. []

SENATOR LATHROP: Thank you. []

RHONDA BOHLING: Hi. []

SENATOR LATHROP: Hello. []

RHONDA BOHLING: Hi. My name is Rhonda Bohling, and I've been here 26 years. I work on a high behavior female unit. []

SENATOR LATHROP: Can you spell your last name for us, Rhonda? []

RHONDA BOHLING: B-o-h-l-i-n-g. I'm one of these people that they talk about with the suspensions, been there about five times, so. In fact, I'd just come back last Friday from a suspension and found out today that they want to freeze me to that unit tonight that Pam was talking about that she got hurt on last night. They want to freeze me there tonight because I don't have my overtime in. Normally I have more than my share of overtime. Every pay period, I always sign up for overtime. I can't sign up if I'm not here. So now they want me to stay because I don't have my overtime. So if you're not here

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you get penalized because you're not here. So... []

SENATOR LATHROP: So your testimony is by way of example of the difficulties people have after a suspension. []

RHONDA BOHLING: Right. []

SENATOR LATHROP: And then they get frozen. []

RHONDA BOHLING: Or even vacation. You can go on vacation and come back and if you don't have your overtime in, you're going to get froze. And it's to units that you sometimes don't feel comfortable working on. I mean or don't know anything about. To me, that's putting me more at risk of getting suspended again because I don't know anything about the unit. And I know nothing about that unit, other than I know who the guys are and what their names are. But I don't know a lot about them, not enough to put me in the position Pam was in, you know, so. []

SENATOR LATHROP: Thank you for your testimony. []

RHONDA BOHLING: You're welcome. []

SENATOR LATHROP: And I don't see any questions and you'll fill one of those sheets out for us? []

RHONDA BOHLING: Yes. []

SENATOR LATHROP: All right. Thanks. []

CHERYL TRIMM: Hi. []

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SENATOR LATHROP: Hello. []

CHERYL TRIMM: My name is Cheryl Trimm, and I am a QMRP at 106 and 108, and I have been an employee here for 11 years. About a year and a half ago, I was put in the acting position of team leader at 108 back when things were kind of blowing up. I just wanted to talk about some of the positive things that have happened. One hundred eight a year and a half ago was a mess. We had lots of restraint usage, lots so suspensions, lots of injuries. And, as an example, cut our restraint usage in half in the last quarter. We have an individual who you could about set your watch by. Every three to five days, we would have a behavioral episode that would end in mechanical restraints. Now we can go 35 to 40 days without that type of instance. I just want to say that I think there's a lot of really good things going on. We have a lot of really good staff. We're not perfect, but we're all working really, really hard. And I think John and Ron aren't perfect, but they're working very hard to, so. That's all I have to say. I just wanted to bring something positive up. (Laughter) []

SENATOR LATHROP: Well, that's good too. We need to hear that. Senator Stuthman would like to ask you some questions. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Cheryl. []

CHERYL TRIMM: Yes. []

SENATOR STUTHMAN: In the 11 years that you've been here do you feel that when you came here 11 years ago there was a few years that it was getting worse, and is it getting a lot better now or since your very positive-type of a lady? Can you just kind of...do you think thing are moving in the right direction now? []

CHERYL TRIMM: I do. I know that we didn't get to this point overnight. I know it's taken many years to get to this point. It's going to take us a while to get back to where we

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need to be, but I think we're moving in that direction. There's a lot of us who are working really, really hard. []

SENATOR STUTHMAN: Do you feel that the communications is better now than what it has been in the past? []

CHERYL TRIMM: I think it's getting better. I think there's always room for improvement. I mean, there's glitches, there's hiccups. But I think as long as we continue to adjust the communication problems and be aware that there are deficits, I think we can continue to improve it. []

SENATOR STUTHMAN: Okay. Thank you, Cheryl. []

SENATOR HARMS: Are there any other questions? You're off. []

CHERYL TRIMM: Okay. Thanks. []

SENATOR HARMS: Thank you. Um-hum. Do we have anybody else who would like to (inaudible)? []

LYNETTE REINKE: I won't take up much of your time. I'm Lynette Reinke, and I had been with the state for 35 years. []

SENATOR HARMS: Would you repeat your name again? []

LYNETTE REINKE: Lynette Reinke, and I first started working at Hastings Regional Center and have transferred here. And so I probably put 10 years at Hastings and 20 years here. I worked ten years on the living units and then transferred to food service. I have had experience with nursing homes, which some of our individuals had been transferred out to. And sometimes I have questions in my head, are we trying to better

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BSDC or are we trying to better our individuals? My experience in nursing homes was not good. It was horrible. The staffing there is worse than here. It's a nightmare. You have maybe 12 or 13 individuals to 1 person that's taking care of them. My husband was in a nursing home for six months. Within six months, he had a bed sore to his bottom full of staph infection, sores on his feet. And at times he was also supposed to be repositioned every two hours, was not. They would come up to me at times and say, we don't have time to put him back in after we've done feeding him. What do you want us to do? Well, at that time they had finally given him a bed that moved himself. Well, what choice do you have? You have to leave it in. So I'm hoping that the individuals that are being rapidly discharged from BSDC is for their better and not for BSDC. And I have one more comment, and that is salary. My children would not dream of coming here and working, not because of the rumors and stuff that are here. It has taken me 35 years to reach the peak of my pay scale. I am now .016 over the top of my scale. My salary still sat. No pay raise this year because I'm at the top of my scale. No cost of living raise the last two years. And I could speak for my sister who's been in housekeeping who did not get a raise for the last two years. Now we all know where gasoline's gone, where food had gone up, everything's gone up. And my one son in comparable wages, but not to this department, but a convenience store starting out at \$9 and hour, and five years later he's making more money than me. That's not an incentive. I've taken two pay cuts in my 35 years, one being a year ago when I had my hours changed due to CMS wanting us to change our hours. So I had to take another pay cut. Thinking, oh, this is an incentive, 35 years dedication to the state and having to take a pay cut. A lot of the people in the food service are upset at their salary. There is a lot of frustration mainly going on on that. I've done comparative job listings that compare to different state-run institutions who perform the same job descriptions as I do, and their wages are different, they're making more money and my question is why. Why are not we, if we're an equal opportunity, why are we not an equal pay between the organizations? And I guess that's my input on the...any questions? []

SENATOR LATHROP: Very good. Senator Harms []

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SENATOR HARMS: Thank you, Senator Lathrop. Have you talked at all with your union or the folks that might be able to help you look at that scale and see what can be done with that? []

LYNETTE REINKE: Well, my coworker was in here earlier and that's where we wanted to know if our job titles could be reclassified. No, because they were too busy. They were negotiating last year for some other employees that deserve a pay raise and were underpaid with comparable wages with other states. []

SENATOR HARMS: And does that work through the union or does that work through management? How does that function for you here? []

LYNETTE REINKE: Well, I'm assuming that it works for through union, through the negotiations. []

SENATOR HARMS: Okay. Do you have someone here who negotiates for you? []

LYNETTE REINKE: Yes. []

SENATOR HARMS: Who determines the priorities of the negotiations? []

LYNETTE REINKE: That I couldn't tell you. []

SENATOR HARMS: Okay. Thank you. []

LYNETTE REINKE: You're welcome. []

SENATOR LATHROP: I think that's it. Thank you. []

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LYNETTE REINKE: Thank you. []

RON STEGEMANN: Good afternoon. I'll fill one of these out when I get done, I promise.
[]

SENATOR LATHROP: That's fine, Ron. Thanks. []

RON STEGEMANN: (Exhibit 5) My name is Ron Stegemann, S-t-e-g-e-m-a-n-n. I am the Chief Executive Officer of BSDC. I had the opportunity to speak with this group the last time that they met up in Lincoln. I appreciate your efforts in coming down to Beatrice today and in giving the employees and folks here in Beatrice an opportunity to speak with you. I applaud everyone who has come up to provide you information today. I think it's important for you to be able to do the task that's been set before you that you have all the available information at your disposal in order to make some of those decisions and recommendations that you've been asked to do. So I appreciate that. I just wanted to address a few things that have been brought up today and let you know how we can get you additional information on some issues. One of the things...some of the investigations that have been brought up today. I know that you've requested information and Jodi Fenner will be able to provide you investigative information for some of the issues that were brought up today. You can look at the investigative reports. You can look at the administrative reviews for those. If you would so choose, we could make the investigative files available for you also, some of which are quite thick and lengthy, but we would certainly get those and make those available to you as well. The abuse and neglect issues that have been brought up today, certainly it is a concern for the facility and for the staff that work here as well. The idea that zero tolerance for abuse is necessary is absolutely true. Within the agreement we have with the Department of Justice now, one of the items that's in there is that we need to develop a policy for zero tolerance for abuse. That policy has already been developed. It's been implemented for quite a length of time. One of the things that's included within that is we also have to report and investigate all injuries of known and unknown origin.

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Based on the level of that severity of the injury, whether it be known or unknown we have to also have to investigate those that rise to a severity level three or four, and we get you those definitions too as well if you'd like to have those. The point had been brought up earlier today about looking at a range of abuse that might be able to occur. When it comes to physical abuse, the standards are very clear. The only option for us organizationally is termination, and the reality of it is whether or not that was a slap that possibly came out of anger from a staff person or a push or a trip or a shove, if abuse is substantiated out of that incident, our only option is to terminate. So whether it would be as much as someone throwing a chair at someone and injuring them or something that we might consider minor could substantiate a physical abuse that is our only alternative. Talked a little bit about failure to report abuse and neglect. We've done a lot of training here at BSDC on recognizing abuse and neglect. The reporting that occurs within the facility are done for everyone that works here. They see things in the course of their daily routines and the course of doing their jobs that make them uneasy, that make them question whether or not that was an appropriate interaction, whether or not it was appropriate words that were used, whether or not it was an appropriate tone of voice. Within that training we do mandate that they do report that to a manager, and then we investigate that fully. Another issue that's been brought up many times is that of allegations being made against staff by the individuals we provide services for. The term "false allegations" has been used a number of different times. We've had lengthy conversations with people from CMS, the surveyors that was here that had been here several different times about what we need to do in those issues. And the reality of it is, and I see it very plainly all the time, is the CMS words are when you find an individual who will make those types of reports that you may think are false, that you may think they're making it up out of anger or because they want to control their environment or they're angry with a staff person, and you don't pay attention to those and you don't do a complete and thorough investigation, what you are doing in reality is creating a perfect victim. We need to be doubly vigilant in making sure that we investigate fully all of those allegations that are made by the individuals who live here. So I wanted to share that piece with you as well. We talked a little bit about the investigations, just kind of some

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information. The investigations themselves, we have a requirement within standards that the investigation pieces have to be completed within five days. We can ask for them receive an extension of that, but it can't be a matter of business. It has to be an extraordinary circumstance, and I would say a huge majority of our investigations are completed in that five-day time frame. That means the investigation is done, the administrator review takes place. Within all of that, then we have to review that investigation, we have to make sure that it was complete and thorough, that all the facts have been brought forth, that all the time lines have been put together, and that is done by review committee. And until that committee has an opportunity to do that review, which typically is the next business day to do that, and then can forward that information to me, if it's an unsubstantiated allegation, then we have the opportunity to bring that employee back. There's steps we've had to put in there ensure that we are being as complete and thorough as possible, that we are making the very best decision based on our knowledge and understanding of what the standards are and how CMS are interpreting those standards to make sure we're making the right decision. And it has to be the right decision every time. We talk about a perfect world sort of situation. CMS does not seem to want to give us much leeway from that perfect world. We need to be as absolutely complete and thorough as possible every time we make those decisions. The additional time that has been talked about...and I think this was given to Senator Lathrop in a letter, I've got some additional copies that I can share that the rest of the committee can have. I think one of the questions was what's the average number of work days to complete an action from date of incident to final completion. Some numbers have been put together between January 1 and August 15, and it was 16.63 days, and that includes all of our suspensions and investigations that take place for abuse, neglect allegations. So some do take very much longer than that based on a number of different issues that arise. And some typically, if it's unsubstantiated, can take shorter periods of time than that. But all of our investigations are put into that average number. There was an issue of budget that was brought up earlier. Just for clarification of those numbers, our budget for fiscal year '08 was approximately \$52,500,000, and for fiscal year '09 is \$53.6 million as indicated in LB321 and LB960. []

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SENATOR HARMS: Ron, could you repeat those numbers? []

RON STEGEMANN: Sure. Fiscal year 2008, \$52.5 million, fiscal year '09, \$53.6 million. Another question that I believe came up from one of you earlier, it may have been Senator Lathrop, was that of the scheduling situations and why we would need to use mandatory overtime. So call ins have been brought up within all of that. We do put out a schedule. I can offer you to be able to see what those schedules look like. I thought I had one with me, but as I look now I don't see that I do have it. But typically that schedule is set up in such a way that it includes regular DT staff and the voluntary overtime, and that our numbers show at least minimum and usually desired numbers of staff across the board within those. What happens though that requires the use of additional voluntary overtime, of the use of mandatory overtime when we absolutely have to are issues such as call ins. Things arise in people's lives and those things happen. The other issue is situations where suspensions take place due to allegations of abuse, neglect. So there are things that arise even after we put that schedule out that does have typically the adequate numbers that we need to run the facility that cause that schedule to be disruptive and that, at times, require us to have to use mandatory overtime. One more thing, and I'm not sure how close I am to my ten minutes, but... []

RON STEGEMANN: You're fine, you're fine. []

SENATOR LATHROP: You get a pass on the ten-minute piece. []

RON STEGEMANN: I get a pass. Okay. I was hoping you wouldn't ask me questions for any longer than ten minutes, but... []

SENATOR LATHROP: That probably isn't going to happen (laughter). []

RON STEGEMANN: I see. Okay. The last issue has to do with administration and

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management of the facility. I, this facility, this administration have been running basically short four very key positions for about the last six or seven months. We are on the process of hiring for those positions. I agree with a lot of what's been said about BSDC and what needs to be done with the organization in order to move forward. One of those things is that we need people to come into this organization who have skill and experience in operating and running ICFMRs. That is my goal overall in filling those four positions that are in the areas of Active 3 Administrator, Quality Improvement Administrator, Neighborhood Services or Residential Administrator, and for the area of Investigations and Client Protections. I have one individual who has been hired. He will be arriving on September 15. He has been recognized by the state of Ohio for his work in ICFMRs there. He is currently in a facility in Florida. He came up and visited with us about three weeks ago, and he will be joining us in the middle of September to provide direction to what we call maintenance services, which provides direction to the assistant administrators, a couple of which have spoken to you today. The managers, the QMRPs, the HSCS, human services treatment specialists and developmental technicians. That will be his area that he will be dealing with when he gets here. I have an interview scheduled with a gentleman from Indiana who will be here a week from today. He is interested in our active treatment services administrator position. I have also been in contact with two different individuals for area of quality improvement, which is a huge undertaking. We want to make sure we get someone in here who has qualifications who has operated within and ICFMR, who has the skills and abilities we need in order to put out a good QI plan so that as we move forward in what we want to be and what we want to do here at BSDC we have accurate measurement of how we know that we're making progress in those areas. The other area that has to do with abuse, neglect investigations and investigations administrator, I'm having more difficulty in finding someone who meets the qualifications we're looking for in terms of someone who has the amount of experience that we're looking for, someone who has recent experience with Centers for Medicaid Services and what they're asking for in client protections and investigations. But we are working diligently on filling those positions so we can continue to move forward. I believe that's all that I have to present. So any

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questions? []

SENATOR LATHROP: Sure. (Laugh) We'll start with Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. Hi, Ron, good to see you. In regards to anger management, we have people that work involved with situations. Do you have anger management courses here? []

RON STEGEMANN: What we do is we employ a system called The Mandt System who's run by David Mandt and Associates. And it is a system of how to interact with people in both difficult and nondifficult situations. But it provides information for how to engage people in deceleration, how to get them to the point where they can manage themselves through a behavior rather than you ever actually having to physically intervene. It does also provide physical intervention techniques when absolutely necessary to protect from harm. So we do do that training here. []

SENATOR WALLMAN: Because I might need it. And going on from that, when you get hurt like that, does he have any medical expense at all? []

RON STEGEMANN: I don't believe so. []

SENATOR WALLMAN: Okay. []

RON STEGEMANN: Since it was at work, I don't believe so, no. []

SENATOR WALLMAN: Okay. Thank you. []

SENATOR HARMS: Thank you, Senator Lathrop. Ron, you're the CEO, correct? []

RON STEGEMANN: Yes. []

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SENATOR HARMS: What are your responsibilities or how do you define your responsibilities? []

RON STEGEMANN: My responsibilities are to provide direction and leadership to the organization. There are a number of different decisions that need to be made throughout the day that rest on my shoulders that have to do with things like abuse and neglect, that have to do...every unknown injury that occurs 8:00 to 4:30, Monday through Friday gets reported to me. All abuse, neglect allegations get reported to me. So it's those things that are day-to-day issues that need to be dealt with. CMS is clear in my responsibility as the administrator of the organization that I need to be involved with and responsible for those. []

SENATOR HARMS: Thank you. So all the complaints that we have read, all the complaints that we have...all the discussions we've had today you have ownership of, is that correct? []

RON STEGEMANN: Yes, sir. []

SENATOR HARMS: If you have ownership... []

RON STEGEMANN: Hang on, can I back up just a little bit? []

SENATOR HARMS: You sure may. []

RON STEGEMANN: Certainly for the last eight months, yes, sir. []

SENATOR HARMS: Pardon me? []

RON STEGEMANN: For the last eight months, yes, sir. []

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SENATOR HARMS: Okay. So we're addressing the issues and from what I've been able to see here, at least what I've been able to read about and then listening to the staff pretty much confirms my thoughts about it, there are major issues in regard to management here. From in between maybe your office and throughout the process people don't feel like they're in power. People don't feel like they've been able to communicate. Their staff live in fear of being suspended. The staff development, there isn't an appropriate staff development. And they also I think just from my observations, they don't know where the organization's going. They don't how we're going to resolve these issues, I mean, how are we going to deal with these issues. You have a lot of people here who are very unsettled, who live in fear, and unless that culture changes, these four people that you're going to bring in will make no difference. They'll help to a certain degree, but there's a lot of work that has to be done in changing the culture and getting back the confidence of the people who are here and knowing that they have good leadership. And I think it's so important or we will fail again. And so I guess what I'm really asking you, what are your goals in these areas and how are you going to get the staff back together to where they can support the mission? You've got great people here. I mean, I was excited about just listening to them and through the miasma. But they're pretty much crushed, and how are you going to get that back as a CEO because that's tough? I've been there once myself and I about didn't get through it. I did finally when I finally wised up. So how are you going to get through this? []

RON STEGEMANN: In what you're bringing forth is true. It is a very difficult situation. One of the things that's been positive in my sitting in here today and listening is that nearly all the BSDC employees that came up here and several of you asked the question, do you think it's getting better. A majority of those staff that came up here and presented information said that they did feel like it is improving. We have a long ways to go. I fully understand that, but we are improving in many areas within the organization. We haven't got to that tipping point yet. We are still working to get there. My best approach to be able to do that is working with each individual that has those issues,

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spending as much time as I can, based on what my requirements are for my position, out speaking to people, interacting with them, becoming involved and knowing what happens out on the living units, talking to the professional discipline staff, working with them on their problems. Is probably going to be the way that I'm going to be able to address that cultural aspect of what's going on quicker than by any policy changes than by anything that gets into the newspaper or anything that comes out from the media in general. It's that interaction that's going to make the bigger difference in how our culture can turn to one of people having confidence in the organization, people having confidence in the ability of the managers, the professional discipline staff, the developmental technicians. I think that's really where the key to that issue is. []

SENATOR HARMS: Well, a lot about your organizational structure here, do you feel that the structure that you're operating from is appropriate and will actually address these issues you're talking about? []

RON STEGEMANN: Excuse me just a minute. []

SENATOR HARMS: And are you...that's okay. You can see I stayed at the Holiday Inn last night. []

RON STEGEMANN: Probably one of the calls I have to take everyday. I forgot to give that to someone first. Could you repeat that, please? []

SENATOR HARMS: Well, I'm just asking basically how you might deal with these issues. []

RON STEGEMANN: Could you repeat what the issues are? []

SENATOR HARMS: Yeah. Well, let's just go back to the aspect of the people who have the unrest. You have people here that have been here for 28 years and they just don't

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feel comfortable at all. People who have been here 30-some years don't feel comfortable that there's enough communication, there's enough flow here. And I guess what I'm really trying to come to grips with, how are you going to get that back and how are you going to make these people feel comfortable? And then on top of that, you have an organizational structure that I want to really ask you about. Is that organizational structure, do you feel comfortable with this structure and will this structure bring you out of the issues you have because you can have these four people that you have, but if a structure doesn't function for you, you're going to have difficulties addressing the issue. []

RON STEGEMANN: I'm reasonably comfortable with the structure that we've designed now. The reality of it is that those people that I've talked about will be the administrative leads within those structural areas. So bringing in people that have experience, that have knowledge in those areas I think is going to be an effective way to address the issues that you've referred to. In essence, what's happening now is we have the good people that have come up and spoke to you today as well as myself filling the void for those few administrative positions at present. And I will be relying somewhat on those folks that I bring in to assist us as we move forward with those cultural issues, with the fact that people have to work in an environment when there is unrest, they're unsettled, they're unsure about their actions. We've been through a huge amount of stress over the last two years. Everyone behind me who works in the organization, myself, all the way up through Chris Peterson, head of Health and Human Services. So I don't think it's unusual that people would feel that unrest at this point. We are still trying to make sure that we do everything perfect so that when CMS returns to BSDC we have our best efforts out there and they can see our best opportunity to make sure that we can continue this organization. []

SENATOR HARMS: Well, just one final question and then I'll leave you alone for a while, okay? []

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RON STEGEMANN: Okay. []

SENATOR HARMS: When I see what you're doing administratively, then I look out here and see the rest of your staff, are you going to make any attempt at all to fill these other positions because people who really are doing the work here, are dealing directly with clients are pretty much beat down, they're pretty much overwhelmed by all of this. What relief are you going to give them and what is your goal there? And then on top of that, what kind of a budget impact is that going to have? []

RON STEGEMANN: What positions are you referring to? []

SENATOR HARMS: I'm talking about the people who are doing the daily work here with staff who indicate there's a shortage. I don't know all the different initials and stuff that were there, but you have a shortage here. How are you going to address that issue so you give them some relief, so you get away from all these issues where they're frozen or however that works and people, you know, don't want to work the kind of overtime they have to work, and so it's evident that you're short. So how are you going to address that issue? []

RON STEGEMANN: We are continuously recruiting and hiring for developmental technicians which are those who provide direct care to the individuals. There is recruitment in retention bonuses that are available for staff that come on board. We've done a very nice job I think since January of bringing people on board that are of a good quality. a good percentage of those individuals have remained. I don't have those numbers here now. But since January 1st, we've had a lot of our new hires that have remained within the organization. We found out that the first six months is very critical to that hiring piece. We have hired an orientation facilitator that will work through that orientation process with those staff. We're in the process of hiring four mentors who can work with and follow those newly hired developmental technicians through at least the first six months of their employment or afterward if needed. They can also provide

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support to veteran staff that are out there to work through issues to assist them with problems within that. For some of the other positions that we have vacancies for, things like nursing, speech therapy, psychology, psychiatry, neurology, a lot of those vacancies the reality of it is the current pay scale that we have available to us will not attract those people to BSDC. []

SENATOR HARMS: So then if we were able to do what's necessary here and that is needed for the clients, have you done any kind of budgetary review of that and what it would entail and how much increase it would take to staff this appropriately? Because I think all these positions you're talking about that you say is because of pay scale does not pay. These are critical to what happens. When you look at all the review...when I read the reviews of the federal government and the things they were saying by the fact that you don't have enough and there's no communication and discussion in regard to meds and follow up and where there's any issues there. These are all serious issues, and people may very well become...you know, can lose (inaudible) in regard to that aspect. And so what are your thoughts about that, and what do you think that budget would take? []

RON STEGEMANN: We have done an additional review of what we think may be necessary based on what's in our Department of Justice agreement. John Wyvill, myself, Jodi Fenner, and others have been working on what we think that increase will need to be. I don't have those exact figures in front of me, but we have done that work, yes. []

SENATOR HARMS: Could you give me just a guessimate? What do you think we're looking at? I'm not going to hold you to it. (Inaudible) Appropriations Committee. []

RON STEGEMANN: You may not, but someone behind me might. (Laughter) I'm not exactly sure. The number that's coming to mind is somewhere in the neighborhood of \$3.7, \$3.8 million per year first year, and then it does decrease slightly after that due to

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recruitment issues and some of those things. But the reality of it is that the state of Nebraska has not kept up with what some of those skilled professionals. And when I say skilled, I guess I mean educated professionals that are licensed and certified, people like psychiatrists. Dr. Zlomke who provided testimony to you folks, I had asked him to do some research and make contacts and figure out if he had anyone who could come to the Beatrice State Developmental Center and provide psychiatric services full time. He was speaking to a colleague that he knew and he said somewhere in the neighborhood of \$300,000 a year, and the guy said I won't even talk to you on the phone for \$300,000 a year. So those people are rare in the state of Nebraska, they're rare nationally, and we're going to have to figure out a way to get them into this organization so we can provide those services to keep people safe. []

SENATOR HARMS: Thank you. []

SENATOR LATHROP: Senator Gay. []

SENATOR GAY: Ron, it sounds like you're making some changes, trying to do some recruiting. But to follow up on Senator Harms, what he's after, I guess I asked earlier Pam or...what do you measure yourself against still? Even if you go higher, some new policies...some directors, whatever the case may be, what you measuring yourself against? Is there a center in the region that's the best? Is there somewhere around the country that's the best? What do you look at? What are you shooting for, I guess? Or are you just trying to stay out of CMS's target? []

RON STEGEMANN: At this point in time we're...I mean, we're doing a lot of things to make sure that we're meeting what's in the standards. And that's what CMS is looking at. I'm not aware of the best. I don't know where it exists. We do a lot of research. We ask a lot of questions. We have organizations that contact us to ask us what we're doing. So nationally, there is a hunger for what is the best. How do we know that we are doing our investigations the right way, that they're complete and they're thorough and

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that we're protection clients as best as we possibly can? At the present time, most of the people that have that information and that knowledge have been involved with CMS on some level, either as a CMS surveyor, a CMS official. And they set themselves up once they've completed that portion of their professional careers in consulting companies. So those are the people that we go to and access for best possible information and best practices when it comes to those situations. We measure ourselves through our QI plan. We have a number of different indicators throughout the organization, throughout the various disciplines in departments that we have to try to make improvements to things like our active treatment audits that we do. It has to do with: mandatory and voluntary overtime hours; the restraint usage, we're always looking for a downward trend in terms of frequency and duration of restraint; mealtime audits, making sure people have access to their items of everyday use and throughout their home. So there's a number of different measurements that look at organizationally through our QI plan that tell us if we're making a positive difference and that we can make decisions based on whether or not that difference is being seen or not. But as far as I know, utopia doesn't exist. []

SENATOR GAY: Well, then how did we know in the '80s that we were one of the best in the country or why did people say that then? []

RON STEGEMANN: Because that's what was placed in the print. I've read the stories. []

SENATOR GAY: Okay. So it's a perception is what you're saying. []

RON STEGEMANN: Right. Well, no I've actually seen in, you know, in different media things and in some books. When I started here in 1989, that's what I was told and so I believe that. And we were a standard of excellence facility for that period, that time. []

SENATOR GAY: Okay. And then on these measurements you're talking about, are those then disseminated throughout the staff that they know exactly, gee, in this measurement we're doing better, we're doing worse? In Children and Family Services

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Divisions there's measurements you can go on-line and check. You know, we're doing better in placements, we're doing better in this. They through it out there and kind of challenged the employees. If I'd ask one of these employees how are you doing on your whatever measurement, is there any way that they can check, that they can take pride in, gee, we went from 20 percent to 80 percent in the last year? Do you share that information? []

RON STEGEMANN: Well, what we do within our QI program is that we ask for that information to be analyzed and collected at the lowest possible point within the facility. So each one of those teams in each of the homes should be looking at their restraint use over time, they should be looking at their active treatment audits. So that information should be available to the team, and that's how they should be moving forward and making those decisions. We also want to accumulate that and make facility information or that data, we bring that together and summarize that, and that's available in a quarterly QI report. I don't know that it's available electronic like on the Web or those things. But we do put out a QI report that anyone can access that they can take a look at. []

SENATOR GAY: So is there competition amongst the teams then that we're doing better than you or is there any...I mean, it's good to have those indicators. But I guess you're not going to act on...I mean, sometimes you've got to share those is what I'm saying. []

RON STEGEMANN: Sure. []

SENATOR GAY: You can collect all the data you want, but no one wants to know or people need to know. Another one, I just got what you handed out, number of employees placed on suspension is 87 since the beginning of this year. []

RON STEGEMANN: Right. []

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SENATOR GAY: As a percent, is that based on...how many direct care employees do you have then? []

RON STEGEMANN: We have at present there is around 290. []

SENATOR GAY: Okay. []

RON STEGEMANN: That's not just direct care staff. []

SENATOR GAY: The suspensions aren't... []

RON STEGEMANN: No. []

SENATOR GAY: Okay. Who else would be (inaudible)? []

RON STEGEMANN: Anyone, including myself, could be involved in a situation where suspension might... []

SENATOR GAY: Are most of them direct care staff? []

RON STEGEMANN: I would guess that they are, but I can't tell you that for sure. []

SENATOR GAY: Well, I ran that through... []

RON STEGEMANN: That's our largest number and they're directly with the clients, so. []

SENATOR GAY: And I guess the question is that I took 87, divided by the 293, it's 30 percent of the employees would be on some kind of investigation or suspension. The question I asked earlier, is that...when we set these policies, what's abuse, what's

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whatever, are we setting them as a state or are we just following CMS guidelines? []

RON STEGEMANN: CMS will tell us that we need to develop policies to address certain things, and one of them is abuse, neglect. And their indication is that you have to, when an allegation of abuse and neglect is made, you have to provide safeguards during the course of the investigation. And the most complete and ultimate safeguard that we can provide is that suspension to separate the staff from the possibility of contact with any of the individuals. We've talked to them about different things we might be able to do other than that. They caution us in doing other things because we place ourselves on, as they refer to it, a very slippery slope when we do that. If we would not suspend someone, if we would maybe move them to a different living unit, let's say there's a false allegation against staff on a unit of very capable individuals that are verbal and maybe have some behavioral issues, and so we say let's have you work in an area where we don't have those difficult behaviors. That's not acceptable. They don't make policies for us, but they tell us what policies we have to make and what they need to address. []

SENATOR GAY: So the policy is better safe than sorry, you're out of here, we'll clear it up, then come back to work. []

RON STEGEMANN: Sorry happens to mean immediate jeopardy, so. []

SENATOR GAY: Yes, exactly. So better set in all the policies basically when it comes to any of these. []

RON STEGEMANN: They shape those policies, I would say that. []

SENATOR GAY: Do we ever review them then and go sit down with CMS and say, you know what, we think we can do it better by this, this, and this? I probably know the answer to this is. No, you can't... []

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RON STEGEMANN: CMS... []

SENATOR GAY: ...since we're paying the bills here's what you're going to do. []

RON STEGEMANN: CMS says we are not consultants. They will tell you if they like it or if they don't, and then they walk away. []

SENATOR GAY: Which is frustrating. []

RON STEGEMANN: Very much so. []

SENATOR GAY: Thanks. []

SENATOR LATHROP: Ron, you said that you started here in 1989. []

RON STEGEMANN: Yes, sir. []

SENATOR LATHROP: And what was the position you started at? []

RON STEGEMANN: At that time I was a psychological services assistant. I had actually worked here one summer in 1985 in recreation also. []

SENATOR LATHROP: What's it mean to be a psychological services assistant? []

RON STEGEMANN: It's the same position now that we call a human services treatment specialist. It functioned a little differently then in that we were under the professional supervision of the psychology staff. []

SENATOR LATHROP: So your education or your training was...what was it before you started? []

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RON STEGEMANN: Bachelor's degree in education. []

SENATOR LATHROP: All right. Then you've worked here since '89 up till eight months ago, and then you became the CEO? []

RON STEGEMANN: Right. []

SENATOR LATHROP: What other positions have you held here besides CEO? []

RON STEGEMANN: That position of PSA evolved into different things over time. We now call it a human services treatment specialist. But I worked with a team at a living unit. As Karen Girch had stated previously, they typically have a case load of about eight individuals do assessments, write the learning programs, teach the staff how to run them, and then monitor their progress within those. At one point, I became what they called a programing PSA for that position at which time whenever anyone new in the organization came into that position, I provided them training, mentoring until they came up to speed with the job and they felt comfortable doing that. I also got involved with the hiring of that position at one point. Following that, there was some restructuring that happened within the organization during the time of a previous CEO which ultimately lead me to the position of a program specialist in our quality improvement department. And the majority of my focus at that point in time had to do with the position of human services treatment specialist and the learning programs that they write and how do they meet the Title IX standards and those types of things. From that position, in September of 2006 when CMS...12 of them arrived on our door on a Monday morning, I became involved very heavily in what the organization was doing in response to and trying to improve services based on that first CMS visit. []

SENATOR LATHROP: So in the year and a half before you became the CEO, you spent your time essentially responding to the surveys from CMS? []

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RON STEGEMANN: Yes. []

SENATOR LATHROP: The population...I have this sheet here you did provide me with different documents in the last week or two, and one of them is staffing information, shows that at first the population of people at Beatrice is down; 329 was the number at the end of last year, and it's now at 364. So you're down 65 people? []

RON STEGEMANN: Okay. []

SENATOR LATHROP: Am I doing the math right? Does that sound right to you? []

RON STEGEMANN: Is that...I don't know what the original date is. []

SENATOR LATHROP: December 1st of '07 versus August 1 of '08. []

RON STEGEMANN: Okay. Yes. []

SENATOR LATHROP: Is it down further from that? []

RON STEGEMANN: Two hundred and sixty three, is that the number you have? []

SENATOR LATHROP: Two sixty four. []

RON STEGEMANN: Okay. I believe it's at 263 at present. []

SENATOR LATHROP: How long has it been at that 263-264? []

RON STEGEMANN: We've been gradually decreasing our census since that time period where the information starts, first of the year. []

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SENATOR LATHROP: Yeah. I'm trying to think. It seems like we got this in June and it was about the same number. If you kind of...well, let me do it this way. When the DOJ report came out, we were still in session, we received information, and the census then was at 308. Am I right? []

RON STEGEMANN: Okay. I don't know when you got out of (inaudible). []

SENATOR LATHROP: And it was the goal of the administration to have the census done. But was it 200, the right sizing thing? []

RON STEGEMANN: Ultimately by the end of 2008. []

SENATOR LATHROP: So by the end of 2008 you want to have it down 63 more people. []

RON STEGEMANN: Correct. []

SENATOR LATHROP: Okay. And I guess my question is in terms of reducing the census or the population at Beatrice, the simpler residents to move happen early. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: You can go to the families and if some raise their hand, then those are the first to be relocated. []

RON STEGEMANN: In very simple terms, yes. []

SENATOR LATHROP: Yeah. But it's kind of a simple process in terms of choosing people. You find the people that are willing to leave first and select them and they leave.

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[]

RON STEGEMANN: Yes, sir. []

SENATOR LATHROP: So your down to 264 and it's getting harder to find people who are willing to leave Beatrice, am I right? []

RON STEGEMANN: Harder to find people that are willing to leave Beatrice and also harder to find adequate services for those folks who do want to leave. []

SENATOR LATHROP: That's an important point is that no one can leave here unless there's services out in the community, and that's one of the difficulties you face in terms of reducing the population here. []

RON STEGEMANN: Very much so. []

SENATOR LATHROP: Do you intend by the end of the year or otherwise in your effort to get down to 200 to have people leave here when their guardians or their parents say I don't want them to go? []

RON STEGEMANN: No, sir. []

SENATOR LATHROP: So everyone who leaves to get your population down to 200 is going to be a voluntary situation. []

RON STEGEMANN: Yes, sir. []

SENATOR LATHROP: And will happen only when there are adequate services in the community. []

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RON STEGEMANN: Yes. []

SENATOR LATHROP: That same sheet shows that it has direct care staff and nondirect care staff. And I think we have an idea what direct care staff might be, some of the folks we've talked to today, the people that are face-to-face with the residents. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Who are the nondirect care staff which seem to outnumber the people that are actually providing the care? []

RON STEGEMANN: That's everyone else in the organization at BSDC. That's housekeeping, food service, lawn maintenance, the professional discipline staff, all other positions included in our approximately 750 employees. []

SENATOR LATHROP: So is the direct care, is that only the direct care techs? []

RON STEGEMANN: Developmental technicians. []

SENATOR LATHROP: Okay. So the speech pathologist lady that we talked to, she'd be nondirect care staff? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Okay. If we go back to December of '07 when we started to see really the acute problems with CMS--I won't say that was the beginning, but certainly it was expanding into a threat to your certification here--Did you or the administration retain consultants? []

RON STEGEMANN: Yes. []

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SENATOR LATHROP: And did you hire some outfit called Liberty? []

RON STEGEMANN: We did. []

SENATOR LATHROP: When did Liberty come on board? []

RON STEGEMANN: We anticipated that CMS would have to come back end of February, first of March. So it would have been approximately 60 to 70 days prior to that. []

SENATOR LATHROP: So before the certification, before CMS informed you that you'd lost your certification, Liberty had been on board for a couple of months? []

RON STEGEMANN: At least 60 days. []

SENATOR LATHROP: And did Liberty Mutual...or not Liberty Mutual, the Liberty (laughter) consults, did they provide you with...were they providing you with expertise as in this is what you need to do to right this shift? []

RON STEGEMANN: They were providing recommendations, yes. []

SENATOR LATHROP: And were those recommendations provided to you in any kind of a report? []

RON STEGEMANN: Weekly reports, yes. []

SENATOR LATHROP: Pardon me? []

RON STEGEMANN: Yes, in weekly and a summary report at the end, I believe. []

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SENATOR LATHROP: All right. Did Liberty also provide you with temporary employees? []

RON STEGEMANN: At the end of the time that they were here, yes. We had three of their employees in administrative positions. []

SENATOR LATHROP: Any direct care staff? []

RON STEGEMANN: No. []

SENATOR LATHROP: Did you at some point or another, and we'll say since the first of this year, use a temp agency to bring in direct care staff? []

RON STEGEMANN: Yes. I believe we use five different agencies. []

SENATOR LATHROP: And at what point did you have the most temporary staff working at Beatrice? []

RON STEGEMANN: I would say approximately 45 days ago, 45 to 50 days ago. []

SENATOR LATHROP: And at 45 to 50 days ago, how many direct care temporary staff did you have? []

RON STEGEMANN: Total or here at any point in time? []

SENATOR LATHROP: Total at your peak, 50 days ago. []

RON STEGEMANN: I would guess we had available to us approximately 65 agency staff. []

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SENATOR LATHROP: Sixty five individuals... []

RON STEGEMANN: Yes. []

SENATOR LATHROP: ...that were provided to you through an agency? []

RON STEGEMANN: Several agencies. []

SENATOR LATHROP: All right. Are those people generally from here? In other words, the temp agency goes out, they advertise for this job, and they draw people from northeast Nebraska or were they coming in from Florida and New York and Kansas? []

RON STEGEMANN: They were coming from as far as Mississippi and as close as Beatrice. []

SENATOR LATHROP: Out of that number of folks, were most of them from around here? []

RON STEGEMANN: I would guess it's probably about a 50/50 split. []

: All right. So when the temp agencies wanted to get people on board, they could advertise and get them on board and make them available to you. []

RON STEGEMANN: Right. []

SENATOR LATHROP: That was your experience? Do you use any temporary direct care staff anymore? []

RON STEGEMANN: I believe we may have three or four still left on campus and they're

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still here based on their individual contracts that we have with them. []

SENATOR LATHROP: I look at this sheet now. In December of '07 you had 318 direct care staff. You now have 293, so you have fewer people. But in the meantime you've had as many 65 of these temporary people available to you. Why are you not using them any longer or why did you need them before? []

RON STEGEMANN: We needed them before because we want to be able to provide temporary relief for our developmental technicians, those direct care staff who have been working so hard and so many hours. We wanted to reduce the mandatory overtime that was taking place, and we were able to accomplish that. That was a period of time in which we were reducing our census and thereby closing some of the homes that we had on campus which allows us then to redistribute those, the staffing resources from those homes out into other areas. So it was used a temporary measure in order for us to do some of the things we needed to do organizationally to get our numbers down, to close the homes that we could to reallocate those staffing resources that we had on board. And then once we had gotten to a more stable situation in terms of staffing, then we could release those. []

SENATOR LATHROP: I'm looking at...you also provided a list of overtime. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: You're familiar with that document? []

RON STEGEMANN: Yes, sir. []

SENATOR LATHROP: And you say that you used these 65 people to get your overtime down and this then that you were at you peak 50 days ago, but I don't see that going down on this. I mean, it went down, but marginally so. []

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RON STEGEMANN: Mandatory overtime, sir. []

SENATOR LATHROP: Well, the mandatory overtime as I understand it is when people...when somebody's been frozen. []

RON STEGEMANN: Right. []

SENATOR LATHROP: So what we heard this morning was everybody's...a lot of people are signing up to get their overtime out of the way so they don't get frozen, right? []

RON STEGEMANN: Right. []

SENATOR LATHROP: And they end up in the voluntary overtime. []

RON STEGEMANN: Right. []

SENATOR LATHROP: And it's voluntary in a manner of speaking because if they don't voluntarily overtime, they're going to get frozen and end up in the mandatory column. []

RON STEGEMANN: It's a possibility, yes. []

SENATOR LATHROP: So ultimately what's important to us is the total amount of overtime which didn't really go down when you had all those folks here, did it? []

RON STEGEMANN: Not necessarily, no. []

SENATOR LATHROP: Not necessarily you agree with that statement or you disagree with it? []

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RON STEGEMANN: I agree with it, I agree with it. []

SENATOR LATHROP: You also have a statement of applications received from January to August of '08, that's another document that you've provided. []

RON STEGEMANN: I've seen that. []

SENATOR LATHROP: You've not only seen it, did your office generate this? []

RON STEGEMANN: I believe that was generate in Lincoln through human resources. []

SENATOR LATHROP: All right. You have presently, this document would suggest, to have a total of 134 full time equivalent employee positions in direct care that remain vacant. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: In other words, if you were going to have all the direct care staff you needed, you'd need 134 more people. []

RON STEGEMANN: That number is based on the number of FTEs that have been allotted for the developmental technician position. []

SENATOR LATHROP: And that was based on a population of 263? []

RON STEGEMANN: No. That's based on the numbers of FTEs that have been allotted for several years. If I had to determine the number of developmental technicians, I would need on board today based on the 263, I would estimate that to be about 385 developmental technicians in order to provide for... []

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SENATOR LATHROP: So almost 90 more than you have. []

RON STEGEMANN: Right. In order to provide for some of the things that have been talked about today, days off, sick time, ongoing staff training during which time they wouldn't be on the floor doing the work that they do, I would estimate that figure to be about 90 people short. []

SENATOR LATHROP: What did the temporary agency do to get 65 people available to you that you haven't been able to do? []

RON STEGEMANN: Pay them more money. []

SENATOR LATHROP: All right. And how much more money did the temporary folks get? You know, what did the temporary agency offer them to get them here? []

RON STEGEMANN: I can't tell you what each of the employees were given by their agency. []

SENATOR LATHROP: You have no idea? []

RON STEGEMANN: No I don't. []

SENATOR LATHROP: No rough idea. []

RON STEGEMANN: I can tell you, you know, relatively what we paid the agencies. But what they paid their employees, I can't tell you. []

SENATOR LATHROP: And temp agencies make money off the difference between what you pay them and what they pay their employee, and you don't know that is? []

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RON STEGEMANN: No, I don't. []

SENATOR LATHROP: Okay. There wouldn't serve any purpose to spread that around, (laughter) right? []

RON STEGEMANN: I don't believe so. []

SENATOR LATHROP: How about the professional positions that remain vacant. Can you share with us what those are? []

RON STEGEMANN: Sure. I have vacant...I do not have a psychiatrist on staff nor do I have one under contract at present. []

SENATOR LATHROP: So if you need psychiatric services, what are you doing? []

RON STEGEMANN: Our medical staff is covering our psychiatric needs. []

SENATOR LATHROP: These are the medical doctors who are not trained psychiatrists, but maybe a better residency or a rotation during the residency in psychiatry? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And they're essentially writing the scripts for the medication? []

RON STEGEMANN: We have also...we're in the process of recruiting...we had a psychiatrist that was here last week. We have a new medical director on board, Dr. Alfred Harrington (phonetic). He brought Dr. Todd Stole (phonetic) down for a look at the facility and an opportunity to sit in and see what we do. We have another psychiatrist who is coming down within two weeks to look at the facility as well. We also... []

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SENATOR LATHROP: So you're hopeful you'll hire a psychiatrist. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: What other vacancies do you have, Mr. Stegemann? []

RON STEGEMANN: Neurology. We do not have...we have an contract with a neurologist, but we do not have enough hours in all likelihood based on what we need to do within that contract. We need speech therapist. We need occupational therapists. []

SENATOR LATHROP: How many speech therapists are you short? []

RON STEGEMANN: I don't have those numbers right here. Five. []

SENATOR LATHROP: Okay. Speech therapist, how about physical and occupational? []

RON STEGEMANN: Guessing, I would guess we probably need three more physical therapists, three more occupational therapists, and we also need a team of what's called...to do dysphagia, which has to do with swallowing disorders, and that requires the use of a nurse. I believe an occupational therapist, a speech pathologist is needed to do those things as well. []

SENATOR LATHROP: Did we cover all the professional or licensed positions? You're shaking your head no. What other ones would there be, sir? []

RON STEGEMANN: Nursing, psychology. []

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SENATOR LATHROP: How many more of these are we talking about? []

RON STEGEMANN: I believe we would have seven or eight vacancies for RN positions on campus for registered nurses in nursing. Psychology, I believe we have three or four vacancies in the area of psychology. Current psychology directors, like Dr. Zlomke, is with us a little less than half time and he's contracted. We are working on bringing those folks on board as well. Other positions...off the top of my head, I guess that covers the majority of where we're very short. There may be others. I apologize if I missed any of those. []

SENATOR LATHROP: No, no, I think you've given me an overview enough so that I can hopefully make a point. And that is as I read the reports, it wasn't just about abuse and neglect. It really is about whether people are getting what they deserve when they get here. And a lot of it's these very services that you're describing that you don't have because you don't have the staff to do it. It's not just about the direct care staff. It's about having enough speech pathologists, it's about having enough physical therapists and occupational therapists and so forth. []

RON STEGEMANN: Absolutely. []

SENATOR LATHROP: Now let's just say since the first of the year, what efforts have been made to fill those positions? Is it a funding thing? You don't have enough money even if all the nurses and the speech pathologists you needed showed up on a bus, could you pay them? []

RON STEGEMANN: Based on the budget I have now, I don't believe so. []

SENATOR LATHROP: You don't believe so? []

RON STEGEMANN: No. []

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SENATOR LATHROP: So is that effecting your recruiting? []

RON STEGEMANN: Yes. The fact the we can only offer a certain amount of money for a position, yes. []

SENATOR LATHROP: But are you even recruiting for those positions if you can't pay them once you hire them? Isn't that what you're telling me? You don't have the appropriations to pay those people if they showed up today to start work. []

RON STEGEMANN: No. What I'm saying is a little different. We don't have appropriations to fill all our current vacancies, no. That's absolutely true. What I'm saying is we're not able to offer, even on our advertisement, an amount of money that would be attractive enough for some of those licensed or certified individuals to come to work here. []

SENATOR LATHROP: What efforts are you making to fill those positions right now? []

RON STEGEMANN: Most of what we're doing in those areas is looking at bringing folks in on contracts. []

SENATOR LATHROP: So going to the expensive temp agency, like an interim or what of those outfits, and paying them over the market for a nurse, and then they find you a nurse and send them in and pay them less. []

RON STEGEMANN: Right. []

SENATOR LATHROP: But you're paying the temp agency more than you pay the nurse if you had just hired her straight out, aren't you? []

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RON STEGEMANN: Absolutely. I can only pay what's based on the pay scale, what's in the structure. []

SENATOR LATHROP: Excuse me, but that doesn't make any sense. (Laughter) []

RON STEGEMANN: I absolutely agree with you. []

SENATOR LATHROP: No, it doesn't, I mean, just as a matter of trying to run the place. Where do you have to go to get the pay scale adjusted so that you can interest a RN or a speech pathologist in coming to Beatrice and working here? []

RON STEGEMANN: I believe that goes back to the Nebraska Legislature. []

SENATOR LATHROP: Do we set the pay scale for the folks that you're going to hire? []

RON STEGEMANN: As I understand it. []

SENATOR LATHROP: Okay. Well, whether it's us or somebody else... []

RON STEGEMANN: Somebody. []

SENATOR LATHROP: Okay. I think that's all the questions I have, and I don't know if that's...Senator Gay's got one or two I think. []

SENATOR GAY: So Senator Lathrop's making a point which if you're on the health committee you understand us or if you live in Nebraska. There's not enough healthcare workers to go around even if you would pay them. I don't think at this point. So you can recruit all you want. We're in a bind if you live in western Nebraska, northeast Nebraska, Omaha, Nebraska we have a shortage. So I don't know paying more, training our younger people to stay in Nebraska. We have all sorts of programs to do that where we

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will give them scholarships, come work in an area. Maybe this is an area that we need to look into in the future... []

RON STEGEMANN: Um-hum. []

SENATOR GAY: ...to come work. Senator Lathrop is getting to a point that if you could get them all in here in a bus and you got your...you said 90 full time, but it sounds like a few more than that, what's the cost of that? []

RON STEGEMANN: What would the cost be? []

SENATOR GAY: What would the cost be if you could go higher than...let's say you did 45 a year for the next two years, what's the cost of that to the pay scale right now that you have? If you could fill those positions, which is sounds like you're having a heck of a hard time. []

RON STEGEMANN: Sure. []

SENATOR GAY: What's the cost? []

RON STEGEMANN: I'd have to have a calculator here in front of me. Forty positions, I would guess somewhere in the neighborhood of \$750,000 to \$1 million a year to fill those positions when you're talking about pay, benefits, training. []

SENATOR GAY: Yup. I'm talking about the whole thing, pay, benefits, training. And that's direct line staff. And then you said you had a few more others you were trying to recruit that they were very hard to recruit, I mean basically. I was just in a...earlier I was in a behavioral health meeting, and the same thing. They're having a hard time recruiting there too. So like I say, this isn't a...I don't know if it's a problem we can fix right immediately. But we can get you...so when it comes down to it, you need the bucks

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to get something done as well. Quality of life. []

RON STEGEMANN: You need dollars to get things done well. We need to do our job organizationally so this is a place that people want to come to work at. And we have to do our job once we get them here in order to make them feel comfortable in their jobs, in order to make them feel secure in those jobs, and so they feel like they're doing good work while they're here. []

SENATOR GAY: Well, and I guess you don't want a ballpark when we talk about money. We don't want to do that, but I would be interested if you can get that information of what actual cost would be to go fill these positions that we say we're trying to fill, and I know you are. I don't say that in a negative way. We're trying to fill them. I'd like to know coming up because we're going to do a budget what's the cost, so. []

RON STEGEMANN: Okay. We have done some preliminary work on that and we should be able to get that information for you. []

SENATOR GAY: Thank you. []

SENATOR LATHROP: We are not going to make CMS happy or satisfied before we fill these positions, are we? []

RON STEGEMANN: We haven't been able to this point. []

SENATOR LATHROP: But that's...I mean, it's right, it's central to the problem that we face with CMS and it's not...we can't wait until the next legislative session, right? []

RON STEGEMANN: Absolutely. []

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SENATOR LATHROP: No. Whatever we need to do to get the pay scale where it needs to be so that you can hire these people, it seems to me we need to do it. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Or we're going to be making another promise to CMS that we don't keep and irritating them even more than we already have. []

RON STEGEMANN: And we've already made a promise to the Department of Justice that we need to be keeping right now. []

SENATOR LATHROP: Okay. Thank you. Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. In just doing a little bit of a calculation, do you think you could hire one of these individuals for \$50,000 a year, these 40 people that you needed? []

RON STEGEMANN: Forty direct care staff? []

SENATOR STUTHMAN: Yeah. []

RON STEGEMANN: Fifty thousand a year? I think so. (Laughter) []

SENATOR STUTHMAN: Think you could? That'd be \$2 million. (Inaudible) that'd be \$2 million, so. []

RON STEGEMANN: That's why I'm in health and human services, numbers (laugh). []

SENATOR STUTHMAN: Okay. Thank you. []

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SENATOR LATHROP: Okay. I think that's it. Yeah. Thanks, Ron. []

RON STEGEMANN: Again, thank you for your time, thank you for coming to BSDC. []

SENATOR GAY: Thank you, Ron. []

ROGER GIRCH: Excuse me, Senator Lathrop, are you finishing up the session with John? []

SENATOR LATHROP: Well, I don't have to, but after John, we'd like to keep it pretty brief because... []

ROGER GIRCH: I'm not brief, but I did want to speak. []

SENATOR LATHROP: Okay. We came here to hear everybody. []

JOHN WYVILL: Senator Lathrop, members of the committee, my name is John Wyvill. I'm the director for the division of Developmental Disabilities. Again, I (inaudible) want to comment that appreciate you all being down here. There's several things I would like you to look at when you're doing your study about trying to address some of the issues. We have issues in terms of recruitment and retention of direct care staff that have a direct bearing, and I would leave it to you to form your own conclusions of whether or not they're valid. Obviously one of the challenges and barriers to employment at BSDC, if you're a direct care staff (inaudible) we're talking about a developmental technician or developmental technician II is relate to the possibility of being suspended and put in your professional life in jeopardy if you come to work here. There is also, not as criticism, is the very fact of the seniority system here with the direct care staff is that the senior direct care staff have preference for vacation. Then that makes it very hard for direct care staff coming on because sometimes they don't get holidays or time off that they want, and that is a challenge for the direct care staff. I think you may have been

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provided earlier information. If listened to the providers they will tell you that they get paid less for their direct care staff than we do. So some of the challenge is not saying the pay is perfect, but we're saying that some of the challenge is in the context of the area. And the challenge is the context offer on the professional arena. But we have found out with the temporary agency folks and with the temporary agency HHS staff that has come here to volunteer that they general they will fear for a nurse or a professional jeopardizing their professional license. So you have that risk for a nurse or a medical professional has gone through school, they're saying no job and their career in line. And that is a really very real fear. So I just want (inaudible) as you embark on your quest is that you realize that not all the solutions to the problem is necessarily monetary. We believe that some of the challenge is that we have hiring here may even be the location. But we would have the challenge even if it was this facility within Omaha or in Lincoln. So as you go through these things, we certainly will provide you with additional information. But don't want you to believe the way here that some of the issues depending on professional care staff and direct care staff is somewhat complex. We certainly welcome suggestions. One of the reasons that the temporary agency staff was brought here was the very dire straights that we were under at one time in terms of mandatory overtime. And that was the issue that was paramount on the direct care staff. It was also a fine line when we talked with other direct care staff that not only had the dilemma that Ron and others get complaints about. They're concerned about their overtime being cut back. And as we deal with the staff and as we deal with the reduction of the census and we're dealing with the other issues, there's going to become a point in which you will be getting inundated with concerns about the reduction of overtime. And I just want you to be aware of that and to share that with you. I don't want to take anymore of your time, but just make you're aware of that and because you're here for the BSDC staff today. []

SENATOR LATHROP: Thanks, John. I think you'll be our last testifier. Is there anyone else? Oh, nope. It looks like we... []

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ROGER GIRCH: I apologize, Senator Lathrop. I... []

SENATOR LATHROP: You don't need to. We're glad to have your input. []

ROGER GIRCH: (Exhibit 6) Thank you very much. My name is Roger Girch, and I presented written statement in case I didn't get a chance to speak. But I also have been listening quite a lot recently, and I do want to make some additions. And my written comments are simple. My name is Roger Girch, spelled G-i-r-c-h. I think you heard from my wife earlier. I came in when she was speaking. I've been an employee here for nearly 30 years. I started here when I graduated from college. I had a bachelors degree in psychology from UNL. I came here to get some experience, to learn what I might want to go on for a graduate degree. I came here and I fell in love with the people who live here. I was treated well by my supervisors. I was...the first day when I came for an interview, my future supervisor took me out to lunch. The administration at that time was very supportive of everything that was done. I was hired very quickly, and when I loved this place right away, I didn't need to get an additional degree. I wanted to spend my time with other things, so that's what I did. I've been in the same job, and HSTS, started as Ron said, it used to be PSA. The reason it was psychological services assistance, and I did put that in some of my comments, was that that was a correction for another thing that many of you might remember, Horachek v. Exon. It was a settlement...my job was created, the PSA position was created in 1978 as a...I believe it was special appropriation even, by legislative action to resolve a problem that was noted then that there wasn't active treatment. In the old days it was called "day programming," it was called things...day programming, day services, that was all a part of what was happening 30 years ago. I believe in my position. I'm not one of those direct care staff. I'm one of those so-called professional staff. We all do the same job. Our job is to care for the people that live here in the best way possible. I get my reinforcement primarily from every day when I come to work and get a smile. I worked with almost every population out here, every population out here, including the severely physically disabled, the behavioral problem...the behavioral issues people currently. Some days it

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was just a blink of an eye from some of my more severely disabled people like my wife Karen works with now. I really do get that reinforcement. That's what I see as a problem. I see the issue that need to be fixed most starts with the Governor. Our Governor does not respect his employees. He has hired administrators who do not respect his employees. Chris Peterson may be part of that. John Wyvill may be part of that. I hope they're not. I trust them at this point in time. So far I have not seen any reason not to trust them. But there is my constant hyper vigilance regarding the possibility that we have people here who may want to close our facility from the Governor on down. The problem John...and John is the one who said this, recently it was noted to me by an administrator that some of our expert consultants felt that they didn't understand why we had the people we had there. They thought we have psychologists, social workers, nurses who are poorer quality because they work here for the low pay. That isn't it. That is a symptom of the real problem in this state regarding services for developmentally disabled. We are not here because of the money. We are here because of the service. That's what human services means to me. Instead of praise and support and positive reinforcement, which is what we are supposed to use to teach the people we care for, the prevailing attitude of the administration has been one of intimidation and punishment. There are two things that I want to bring out, both of them are personal. I use sick time. We recently in this month we had an attendance policy that was implemented. I am a member of NAPE/AFSCME, I'm a member of the board of directors, and I'm a bargaining team. And Senator Harms, several of your questions I could answer, many of those that you asked Ron regarding those bargaining issues. The attendance policy should be bargained. It wasn't. Chris Peterson decided to enact it, and her administrators decided to start it in August. There are guidelines in that policy that are going to punish people for having sick children, that are going to punish employees for oversleeping because they worked two shifts yesterday. The first shift employee that may have worked until 11:00 last night if they come in 10 or 15 minutes late today, that's going to be counted as a tardiness. So we have this attendance policy that doesn't work for the people that work here. That to me is intimidation. All that policy talks about is how we can discipline the employee, not how we can reinforce them. If

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attendance is so important to our administration, then why are so many employees on extended leave, i.e. investigatory suspension? I didn't want to be repetitive, but I have to be repetitive because that's the important part of what I wanted to say. It happened to me personally last year. I heard Rhonda talking about here fifth time. I work with Rhonda. I've only been on suspension once, last September, October, and November. It was for an incident of client abuse, neglect. I would be very happy to be very specific about that, except for the person's name of course. But what happened was I was investigated. The process...it was a minor...fairly minor issue of a person who was locked into his home. People left and he was in his room, and he had the right to be in his room. But someone locked the door to the home on the way out. I wasn't the one, but I was the first one accused. I spent that month on investigatory suspension, month plus six weeks, waiting for my sentence as any convicted criminal. It was not a good feeling to me. It was not a good feeling. It was not good for my emotional and physical health. It was not good for my family. It was not good for my coworkers because they didn't know what was going on, although of course the rumor mill tells you everything. And it was definitely not good for the individuals I serve because they care about me. They ask about me. When I came back to work today with this, everybody wants to know what this is from. They're concerned. They knew I had surgery. They know what was going on with me. But I did return to work after a second investigation that was brought on because some outside agency didn't feel like BSDC had done quite a good enough job of investigating this horrible crime. I wish that other people were not afraid to speak to you, and I think maybe some of them aren't. I've been working very hard to get many people to talk to you today, and I really do appreciate hearing from some of my coworkers. I'm very grateful for the opportunity to talk today. Your attendance here shows that you care about us, and I as an employee really respect that and want you to know I'm supporting you. I look forward to your report in December. I'm really looking forward to see what kind of recommendations because I think that what your findings and your recommendations are will make the difference at this facility. We've got a good CEO. Ron is good. I think some of your questions, Senator Lathrop, were questioning his level of expertise and his ability. He's got the skills. He just needs the support from

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above him. He also needs the support from us too. I hope I can do that. John Wyvill also has been very positive here. But we do need you. You guys are going to probably hopefully come up with some recommendations for legislation that I will be at your debates next year when you're debating those bills that I hope you guys introduce. Thank you so much. And of course if you have any questions... []

SENATOR LATHROP: I don't think we do. []

ROGER GIRCH: Thank you. []

SENATOR LATHROP: Thank you. []

ROGER GIRCH: And I'll fill this out from back. []

SENATOR LATHROP: Great. []

ROGER GIRCH: In case someone else needs to speak. []

NETTIE GRANT-SIKYTA: (Inaudible) a little bit short. My name is Nettie Grant-Sikyta. I'm here to provide my testimony of support for BSDC. Thirty-five years ago today my son Corey Pen (phonetic) came to live here. Today's my birthday. He was three months old. Kind of ironic that it happened to be...that I would stand here or sit here before you and give this testimony, but it's appropriate. My son Corey (phonetic) was born diagnosed with mental retardation due to rubella. I lived back on the home reservation, northeast Nebraska. We were members of the Omaha Nation of Nebraska. I'm also an employee of BSDC, been with the state 21 or 22 years. My son Corey (phonetic) when he was born, he was severely profound physically and mentally retarded, mentally and physically retarded. Corey was born in one of our IHS hospitals, resources were pretty limited. When Corey (phonetic) was born, he immediately had to go into intensive care. He had very limited movement. Of course he had to go to University of Nebraska, and

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then I really didn't know what mental retardation was until about a week later. I was too sick to go to the hospital with him. But during the next couple of weeks I got to go home, he got to come back to our local IHS hospital and I learned a little bit more. What I did learn is that after I gave birth to my son they were going to wheel him out in a little cart, put him on his little bitty ambulance, and take him down to the university, and I pleaded with the nurse and doctor if I could hold him. I got to hold him for about a minute. They had to wheel it in, bring him out, I got to hold him, that was it. Next couple of weeks I learned what mental retardation was, I learned what rubella was. I had a whole scan of tests and diagnosis done on myself and my husband at that time. During that next couple of weeks, they explained to me that Corey (phonetic) wasn't able to swallow. He had a breathing difficulty. His face was disformed, his ears and his limbs. He can only move right here. Couldn't move his head side to side. His body was very small, fragile. He looked like a little bird, even though he was, you know, full term. Went to the university a couple of times, brought him home. They explained to me that I would have to learn how to tube feed him. Okay. I was married early, barely...didn't even finish my high school diploma at that time. Tried to take him home, tube feed him, take him back to IHS hospital, 30 miles every night. I did that for three days, and the second night I messed up, I didn't know what I was doing. We got him back on schedule, kept him, let me take him home next day. I did that for three nights. It was really difficult. I didn't have the skill. I didn't have the knowledge. I didn't have the know-how. And I realize that I didn't really know what I was doing, except that I had a son that was born with disabilities. When we made the decision to come to BSDC, Beatrice State Developmental Center, I was very happy and to this day publicly will acknowledge the work and dedication, not only in this facility, but also one particular social worker. Her name is Nancy Mayfield (phonetic). If it wasn't for her beside me as a family, I don't think I could have done it. Nancy (phonetic) was very caring and knowledgeable, patient, and she helped us through that. I could barely sign my name (inaudible). And with that, having a child that's disabled or any type of (inaudible), what I've been told is a marriage will either become stronger or become weaker. I have since (inaudible) married for a number of years, 27 years. I'm happily married and my husband is very supportive of me and also works

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here. Thirty-five years ago when Corey (phonetic) was not able to (inaudible) survive, he couldn't swallow, he couldn't move. But we had 24-hour care here. It was called "pizza nursery." It was on 203 Kennedy. It was large. Thirty-five years ago when I came here I was scared. I'll be honest with you, I'd never really had any type of involvement or introduction to people that were developmentally disabled. But since that time things have changed. Thirty-five years ago when I come on campus I was...it was all new to me. You go to different parts of campus. It was all new to me, and I was scared. Different types of individuals with different types of disabilities and (inaudible) and knowledge and behavior problems. And if it wasn't for Beatrice State Developmental Center my son would have died. I attribute my son's survival to this place. We thought Corey (phonetic) as not to live past six years old, and I counted the years. I (inaudible) I'll just come here to see him. I would send a social worker and we would come in by phone. But I worked diligently to find out about the community. What is mental retardation? What do I do? There was no doctors out there. You know, there were really no doctors to know really what developmental disability was, mental retardation. But with the team that we did have and Nancy (phonetic) helping me understand my role in my life and the support that I can give to Corey (phonetic) while he lived here. I had an active role as much as I was able to do so. We had a special friend for him at the time. I had to give my permission and, you know, dot my eyes and cross my tees. With Nancy's (phonetic) help, I wanted Corey (phonetic) to participate in that program, and he thrived. It was a good program. I think that program needs to come back in place. My son was able to go home with his special friend here in this community as well as that person's home community. People in the community knew my son. He was able to go outside, outside of BSDC to function. He grew. (Inaudible) able to swallow because he can eat (inaudible), he was able to move. I have pictures of Corey (phonetic) when he was able to be in a walker. They even had him in a good ole tricycle with a support back. He was able to wheel himself. Physical therapy. He learned sign language. There was so much here that Corey (phonetic) benefited from. He has a psychologist on staff. The team at time...I didn't know everybody. I didn't even know their roles. That was a little bit confusing to me, a little bit intimidating. Since that time as I served as an HSTS

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here, health and human service (inaudible) specialist, I advocate for parents. I'm not going to shy about that. I advocate for parents. I advocate for the guardians because they are a major piece of that team. They are. We need to hear from them more often, not to feel like if I say anything, they might make my son or my daughter leave. I don't have the support at home to take care of them, and I am a part of other groups of parents. I have done work outside of BSDC. My son did live past six years old, and staff...I didn't know the staff at 203 Kennedy. I went to school, I went back to school, finished high school, finished my college. I wanted to come back to BSDC. I wanted to come back to 203 Kennedy. Who are these people? Who took care of my son the first nine years of his life? He turned nine in May of June 1, I took him home. There is no education raising a child with developmental disabilities. The ride home was my first experience and I can tell you that he learned sign. He was able to walk. He was able to see at that time. He grew and I'm very thankful for BSDC for taking care of my son. And I don't mean bath and feed him, that type of daily care. I mean take care of him, help him to grow and to survive and nurture him to the degree of where Corey (phonetic) knew sign language. Corey Pen (phonetic) may not be able to answer a questionnaire, but Corey Pen (phonetic) certainly can tell you what he wants and doesn't want, what he likes and doesn't like, and what his skills he has and doesn't have. And I attribute that to BSDC. BSDC has been a strong influence in my life and in my son and in my family's life. It drove me to go to school, to come back to BSDC to go 203 Kennedy, meet the staff that took care of my son. I had the opportunity to go up there and find out what is this place about, who are these people. I had a chance to meet one, two people that remembered him. And best of all, I got to work for some of the individuals that lived with my son. That meant an awful lot to me. I consider BSDC my home agency. I'm not shy about it. I realize that we're not where we were before. I know that. I know that we've had some difficulties, to say the least. But I do know that we can go back, get back to where we were, even better to where we were 35 years ago, 37 years ago. But in order, in my opinion, in order to get to where we were before is to go back to what did work, find out (inaudible). Why did it not work? Or find out the things that didn't work about it and make the changes. Right now currently as an HSDS we put an awful lot in direct

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care staff. When Corey Penn (phonetic) lived here, we had 24-hour nursing care that took care of the individuals that get their nutrition by tube. We have direct care staff doing that. We have direct care staff can only be responsible for the medication, the nutrition, everything, checking their refrigerator temperature to their daily chair needs to their programming money. We put an awful lot in direct care. I think we can't overstate that. We do have a need for direct care. We have need for qualified, knowledgeable trained staff. We need to have back in place a system of where management or administration will start support staff to go back to school, provide that type of training, validate our staff, help them become better at what they can do. Recently I found out...I'm sort of upset about it, we have individuals that have left campus that have gone into the community. With the decrease of individuals in the homes, we have a mandator staffing. For example, seven. Well, the number of individuals that have left campus for certain homes I've learned that, oh, now the mandatory is not longer seven to six. Okay. But it wasn't issued before. Was it issued before to provide the adequate and staffing for this individuals. So why did that number go down? Why did it not provide the right staffing ratio that we needed before the individuals moved? I think it should have saved mandatory staffing for the individuals for that unit should have stayed what it was at, not change it. I think there's a lot of things that were in place here that would benefit to come back, which in my opinion is to found that committee and find the knowledgeable historical staff that have (inaudible) years. Because you've worked here a long time doesn't mean that you are the ideal staff. Staff that really have dedicated staff, knowledgeable staff to help you, help us to get back to where we were because we can be. We can be a state of the art the way we were before. Staff don't only help to provide individuals with their daily care, they run programs, they help individuals become more independent, what we are all about, the active treatment. We also have staff and management that really don't understand what active treatment is. They don't. I'm sorry. We also have some staff that do have a (inaudible) to active treatment. Active treatment is not just a word on a piece of paper. Active treatment is 24/7. I have some concerns (inaudible) management. I think what we need to do is evaluate whether our...that the individuals, the staff we have in place really have that knowledge, the training, the

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expertise to be at the helm. And I'm not saying Ron. I'm saying management to be at the helm of the facility to get us back to where we need to be. The individuals that live here and the individuals out in the community, we're all on the same page. We should be. But there is going to always be a need for a place like BSDC. You'll see that an option is (inaudible) for BSDC should ever close. Ron needs our support. Roger's correct. He needs our support. I, too, have my reservations for our leadership at this point. I have my reservations and my concerns, my apprehensions. But you also have staff here, and I'm not just saying direct care staff. We have staff here across campus that are knowledgeable, across all disciplines, all disciplines. You've got staff here for example in this center, in this center here that have been here for many years that know what works and what doesn't work. You've got staff here that know individuals that have been here when they were babies. So you have the longevity dedicated staff. And I really ask that you form a committee of where you can have staff that can give you that right type of input and make a safe environment for staff to speak freely and not worry about any repercussions. I'll close with that and I'll apologize if I duplicated anything that someone else may have said. []

SENATOR LATHROP: No, you did fine and we appreciate your testimony. Thank you very much. []

NETTIE GRANT-SIKYTA: Thank you. []

SENATOR LATHROP: It doesn't look like there's any questions, so I think that wraps it up. Thank you all for coming out today and participating. I know that there was in some cases folks had some apprehension, some of it very natural, some of it maybe happened to do with public speaking. But we're all glad you stepped forward because the more we hear, the better informed we are and the better able we are to make judgments and policy. So thanks again and we'll see you soon. []

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The Developmental Disabilities Special Investigative Committee met at 9:00 on Friday, September 19, 2008, in Room 1524 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing regarding Beatrice State Developmental Center. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Abbie Cornett; Tim Gay; Arnie Stuthman; and Norm Wallman. Senators absent: None. []

SENATOR LATHROP: (Recorder malfunction)...everyone. My name is Steve Lathrop. I am Chairman of the commission established by the Legislature pursuant to LR283 to investigate and to study issues related to the delivery of developmental disability services to folks in the state of Nebraska. Today we are going to visit and hear testimony regarding oversight, surveys, reviews, what the process is to...for government to check on how people are doing, whether it's at Beatrice or in the community-based programs, how...what government does to make sure that the people who are receiving services are in a safe environment and that they're cared for the way we expect them to be cared for. And for that we're going to hear from some folks from the licensing arm of Health and Human Services that have some responsibility for that. I might add before we begin that we wanted to have by today, we hoped to have, CMS in here to talk about the surveys that they've done. They've been very involved in doing surveys at the Beatrice Development Center, particularly since 2006, and they've been unwilling to do that. I've asked Governor or, rather, Senator Nelson to help me persuade CMS to come in and so far the best we've been able to get is an offer to come in some time in late November to meet with me and me alone. So we're still working on that. Hopefully, we'll hear from CMS, but I just want you to know that, some of you I've told that we were going to have them in, we're having trouble getting them here, trouble getting them to cooperate and notwithstanding the best efforts of Senator Nelson. We will hear today from Helen Meeks initially, and I think you'll find that we have some people here in the state of Nebraska that are nationally recognized for their ability to do surveys and their

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ability to oversee the care provided to folks with developmental disabilities. So we hope to learn a lot from listening to Helen and Dr. Schaefer as well, both from Health and Human Services, in their licensing arm. And we'll have a little testimony so that you know that these two have a Chinese wall between the folks in licensing and John Wyvill, whose responsibility it is to run developmental disability services. So with that, let me also introduce my colleagues: Greg Adams is to my left, who is the senator from York; Tim Gay to my immediate left from District 14 in Sarpy County; Doug Koebernick is my legislative assistant; Senator John Harms is from Scottsbluff; and Beth Otto is our committee clerk. She's going to make sure we do everything the right way and she's given me a list of things to read and I haven't read it, as you can see, and I don't know if it irritates Beth or not but... []

(UNKNOWN): (Inaudible). []

SENATOR LATHROP: ...one thing she'd want me...(laugh) yeah, because it starts to sound like a stump speech up here. One thing we'll ask you to do is, if you're going to testify, you have to speak up so everyone can hear, adjust the microphone and that sort of thing, but we also need to have you fill out a sheet so that Beth has the information she needs to make sure we have a good and clean and clear record, and we can track you down if we have questions. So please make sure you fill those out and...what's that? []

BETH OTTO: Cell phones. []

SENATOR LATHROP: Oh, yeah, cell phones, if you have a cell phone, if you wouldn't mind turning that off so that we're not interrupted, same with the pagers. And with that, I think we'll start and our first invited speaker would be Helen or Dr. Schaefer? []

JOANN SCHAEFER: I'm starting. []

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SENATOR LATHROP: Okay. That's good. We'll start out with Dr. Schaefer. []

JOANN SCHAEFER: Good morning. []

SENATOR LATHROP: Good morning. []

JOANN SCHAEFER: (Exhibit 1) I am Dr. Joann Schaefer, S-c-h-a-e-f-e-r, and I'm the chief medical officer and the director of the Division of Public Health. The Division of Public Health has numerous responsibilities for the health of the public and one of those is the regulation of healthcare facilities and healthcare professionals. Under the Uniform Credentialing Act and under the Health Care Facility Licensure Act, the role of the director of the Division of Public Health is to oversee the regulation and licensure functions of the department. The role of chief medical officer is to be the final decision maker in contested cases where the Division of Public Health has taken action against an individual or entity for violations of the public health regulation and licensure requirements. Because I hold a medical license in Nebraska and I am the director of the Division of Public Health, the Health and Human Services Act provides that I also perform the duties of the CMO. The Division of Public Health is distinct and separate from other divisions in the Department of Health and Human Services that are responsible for overseeing entities that Public Health regulates. The divisions do not share employees, nor do they have access to electronic communications or documents, paper files, or any other data that would interfere with the separation of the divisions that is necessary and required by CMS to allow the Division of Public Health to maintain regulatory oversight of these state owned and operated facilities. The directors of other divisions have no more say in the regulatory process of the Division of Public Health than the public participants in our rule and regulation hearings. It is also important to note that the CMO's decisions in contested cases are not subject to review by the executive branch officials, whether that be the CEO of DHHS or the Governor. These decisions, which are basically the final decisions in regulation and licensure enforcement actions, are reviewable only by the courts. My unit administrator, Helen

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Meeks, will testify next to explain the survey process and provide some definitions and share the relationship with CMS and how it relates to our role. As you are aware, we've been out on many surveys to BSDC, as well as our other ICF/MRs within the state of Nebraska. We have been out on complaints, annual surveys, and revisits, all of which have been unannounced. We have shared copies of the findings of our surveys for the last ten years with you and can answer questions regarding those and the survey process in general. But first, I'd like Helen to explain the various types of surveys we perform and the oversight of us by CMS. I appreciate very much the ability to be here today and explain that to you guys. []

SENATOR LATHROP: All right, Dr. Schaefer. Before we see if anybody has any questions, I want to... []

JOANN SCHAEFER: Sure. []

SENATOR LATHROP: ...let folks know we've been joined by Senator Wallman. Glad to have you here today. Dr. Schaefer...anybody have any questions? Just so that...you and I have had some conversation, I want to make sure it's clear... []

JOANN SCHAEFER: Sure. []

SENATOR LATHROP: ...what your role is in the big scheme of things. When we look at a place like Beatrice, which is an ICF/MR, or the community-based programs, to the extent there is oversight by the state, it's done by your office. []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: And what you've explained to us is that you are...even though you are technically part of Health and Human Services, you are...there is a wall between you and the folks that run Beatrice so that your ability to judge how they're

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doing is not compromised. []

JOANN SCHAEFER: That's correct. []

SENATOR LATHROP: And the person who's actually doing those surveys would be the next speaker, and that's Helen Meeks. []

JOANN SCHAEFER: That's correct. []

SENATOR LATHROP: Okay. Senator Gay. []

SENATOR GAY: Dr. Schaefer, you know, I understand how we do that, but do other states? Are we like other states? Is that what everybody does, where we have a separate and distinct branch or...? []

JOANN SCHAEFER: Yes. []

SENATOR GAY: Is there other methods that we could use? Most states have it set up that way, where their chief medical officer or somebody within a department regulates. []

JOANN SCHAEFER: Right, and within a department or an agency, regulates the other side of government, which has the ownership and operation functions of those facilities. []

SENATOR GAY: And that meets the CMS guidelines. []

JOANN SCHAEFER: Right. []

SENATOR GAY: But...so no other states do it any other way? []

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JOANN SCHAEFER: Not that I'm aware of. []

SENATOR GAY: Okay. []

JOANN SCHAEFER: I can certainly check, but if the CMS designates us to be the survey agency of the state, whoever has that responsibility must be separate and distinct. []

SENATOR GAY: Yeah. []

JOANN SCHAEFER: In fact, when we went through the Health and Human Services Act, that was one of the things we had to do, was submit the language and the charge to CMS to make sure that they were okay with the way we were setting up the department, that they didn't see a conflict. Because if you look at it straightforward on the organizational chart, it looks like there very much could be a conflict. []

SENATOR GAY: Sure. Yeah. Well, you don't need to check. We'll check it. []

JOANN SCHAEFER: Okay. []

SENATOR GAY: As long as everyone else is generally doing it that way,... []

JOANN SCHAEFER: It's generally the same. []

SENATOR GAY: ...that's all I wondered. []

JOANN SCHAEFER: Everything...every one of my colleagues that I've talked to,... []

SENATOR GAY: Yeah. []

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JOANN SCHAEFER: ...if they have a regulatory responsibility. Not all chief medical officers do, but some of them have a completely separate person that does that. []

SENATOR GAY: Okay. So as we go throughout the day, this is just standard what everyone is doing then. []

JOANN SCHAEFER: Yes, pretty much. []

SENATOR GAY: All right. Thanks. []

SENATOR LATHROP: I do have a couple more questions that I thought maybe I could... []

JOANN SCHAEFER: Sure. []

SENATOR LATHROP: ...ask to clarify your responsibilities. As a licensing agent, a place like Beatrice, in order for it to even open its doors, it has to be licensed by...and that's your responsibility to license it. []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: Is that true? []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: And if we look at a facility operated by Mosaic or ENCOR or another one of our community-based providers, before they can begin operations they have to be licensed, which means they go through an inspection. []

JOANN SCHAEFER: Yes. []

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SENATOR LATHROP: So if we look at the opportunities your office has to be involved in evaluating the care provided, whether it's at Beatrice or in a community-based program,... []

JOANN SCHAEFER: Uh-huh. []

SENATOR LATHROP: ...those opportunities are first when they are licensed. Is that right? []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: And second, when you conduct a survey? []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: And a survey is kind of a term of art, but basically that's an inspection, is it not? []

JOANN SCHAEFER: Absolutely. []

SENATOR LATHROP: Okay. And then the third opportunity is if there's a complaint... []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: ...you might go out and do an inspection or a survey in response to a complaint. Is that right? []

JOANN SCHAEFER: Yes, that's correct. []

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SENATOR LATHROP: So there are licensing surveys, some of which are random... []

JOANN SCHAEFER: Uh-huh. Right. []

SENATOR LATHROP: ...where you just show up at a place, and then responding to a complaint. []

JOANN SCHAEFER: Right, or going out on a revisit on a complaint that we've already established that there's a problem. They've done some things to correct it. We may go out on a revisit survey as well. []

SENATOR LATHROP: And that's a good point. If you find a problem, if your inspectors or your surveyors, and Helen will explain this I'm sure momentarily, but when you find a problem you develop a plan of correction with the institution or the facility, and then a revisit is to see if they actually did what they promised to do. []

JOANN SCHAEFER: That's correct, yes. []

SENATOR LATHROP: Right? []

JOANN SCHAEFER: Yep. That's exactly... []

SENATOR LATHROP: And that's basically the process. []

JOANN SCHAEFER: Yes. You've got it down. []

SENATOR LATHROP: Maybe take a second and share with us what your relationship is with CMS. You do a survey or an inspection and you share that with CMS and they share theirs with you. Can you kind of tell us how that works? []

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JOANN SCHAEFER: Sure. All of the information that we put...and all our survey pieces are put into a central database or, you know, a computer that talks with CMS, so they have the ability to go on and look at our surveys at any given time. In addition to that, you know, when we ever have a question about any of the findings that we may have in a survey, they're always available for consultation. They've designated us as the state agency for being the ones to do the regulation on all of these, so that they're handing us that duty. At any moment, they could take that duty away if they weren't happy with what they were seeing or if they wanted to go back and do some checking themselves, but we've maintained that duty. Sometimes there's a slight discrepancy between the definition of what you'll find as far as a deficiency and the way they define it, the way we define it, and we have to go back and forth and kind of argue out the cases and see who really has the correct way of defining that deficiency. We just had a survey or a CMS review yesterday, actually, on our intake process. They were looking at two of the functions that we do where they compare how we triage and they compare the quality of our investigations and they review those. They score them. They're done on a percentage basis. They pull charts randomly. They just come in. We have it, usually, yearly and then we get the results from that. So if they see areas where we're not performing well or they think that there are issues, they point them out for us and then they give us opportunities to correct them or do some additional training and make sure the surveyors are up to speed. And they actually call it correctly on-site when they're writing the deficiency. []

SENATOR LATHROP: Okay. I have a few more questions and that is maybe to give people an historical perspective. You were kind enough to provide ten years worth of information in response to requests made by this commission and we've gone through an awful lot of the documents, one or which basically revealed to me that your office has been primarily responsible for doing the surveys of Beatrice up to a point in about 2006. Is that right? []

JOANN SCHAEFER: That's correct. []

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SENATOR LATHROP: I mean, if we looked at how many were done by CMS and how many were done by your office, mostly you were doing that work up to 2006. And then we see CMS coming in and doing a large number of surveys themselves, probably in cooperation with your office. But they became the primary person to do surveys... []

JOANN SCHAEFER: That's correct. []

SENATOR LATHROP: ...since 2006. []

JOANN SCHAEFER: Yeah. We've been doing more with them more recently,... []

SENATOR LATHROP: Okay. []

JOANN SCHAEFER: ...but, yes, you're correct. []

SENATOR LATHROP: And just to maybe give you a pat on the back, I saw that there was some concern in your own mind, in an e-mail perhaps that I read, as to whether or not CMS stepped in because your office wasn't doing a good job. []

JOANN SCHAEFER: Sure. []

SENATOR LATHROP: In fact, that wasn't the case. []

JOANN SCHAEFER: Right. []

SENATOR LATHROP: You guys have been doing it the way you should. You'd been doing it in an acceptable way. And they actually used some of your people to help train people on how to do the surveys. []

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JOANN SCHAEFER: Yes, that's correct. []

SENATOR LATHROP: So when we see the surveys done at BSDC go from primarily your office to primarily CMS, that didn't have anything to do with the quality of your surveys. []

JOANN SCHAEFER: Not according to any feedback that we've received. No. []

SENATOR LATHROP: Okay. Okay. That is all that I have, if anybody has... []

SENATOR HARMS: I just have one question. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: The surveys that you do, you identify where there may be issues and problems? []

JOANN SCHAEFER: Uh-huh. []

SENATOR HARMS: The question I have is how could we get ourselves into this environment that we have today with you looking at and surveying and identifying what the problems are? How could an organization go so far astray? It's just staggering to me every time I read these reports and look at the documentation. It just pulls at my...tugs at my heart to try to understand how we got here. Could you explain or give me any... []

JOANN SCHAEFER: Well, from my perspective or vantage point, you know, I look at this has been a ship that kind of slowly veered off course. And although the survey process is there to, you know, to check on all the things that we're supposed to check each time that we go in or based on a complaint, you know, many times those things can be addressed, answered, corrected at that time, but those are only during the times

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that we're there seeing a specific window. That doesn't mean that during other times other things aren't happening that we're not there to see. And, you know, the complaint process actually works fairly well to take care of anything that is egregious, but I think a slow turn off course is probably the best way, if you look back over the last ten years, because there have been consistent deficiencies cited within the ten years of surveys that we've provided. But I think that to get to where it is now it does boggle the mind. But I think everyone has a role in that. []

SENATOR HARMS: Okay. Very quickly, the other question I would have then, once you identify the issues... []

JOANN SCHAEFER: Uh-huh. []

SENATOR HARMS: ...and identify this as a concern, and I'm sure there are other things that are going on at the same time, it's hard to get your hands around, it's the same question I've asked everyone and it's still in the back of my mind, comes back to the...it comes back always to the issue of management. It comes back to the issue, who's in charge? []

JOANN SCHAEFER: That's true. []

SENATOR HARMS: It comes back to the issue, do we have the appropriate staffing? It comes back to the issue, do we have the right credentialed people there? And that's how I'm beginning to sum this up. I just...I'm just kind of interested, since you've been there and you've watched this, what are your views about that? []

JOANN SCHAEFER: Well, I think there's definitely some truth to that. A slow change in leadership, a change possibly in culture, maybe slipping away from some of the best...standards of best care that are being done nationally and having leadership, may not be up to date on some of those things over time. And maybe it's so slow that people

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don't realize or haven't realized that it's veered off course so much until they turn around and they look in the past and they can see where it's gone and where their peers are in other states. []

SENATOR HARMS: Let me ask you another question. In regard to the culture,... []

JOANN SCHAEFER: Uh-huh. []

SENATOR HARMS: ...could you give us any idea or suggestions of how that culture can change? Because I know that's really a difficult task... []

JOANN SCHAEFER: Uh-huh, yes. []

SENATOR HARMS: ...in any organization, particularly a troubled organization. []

JOANN SCHAEFER: Sure. []

SENATOR HARMS: What would you recommend to this commission about how to change that culture? Because it is...you know, we can make all the changes we want and recommendations, but if that culture doesn't change we'll be back here five years from now having the same discussion. []

JOANN SCHAEFER: That's true. You know, culture change, as you said, is very difficult to do, but it has to be very driven by the fact that it's...patient safety has to be, you know, up there, and you have to be able to ensure that the people that you are taking care of are your primary responsibility and that everyone is appropriately trained to the level that they should be and can provide the services that they're supposed to be according to their job title. Change in culture can, you know, take anywhere from outside companies coming in and telling you how to do it, to being very persistent but getting a positive culture. This is a staff that's been beaten down on quite a bit and has

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had a rough go of it as well. And so, you know, John has done a really good job of uplifting them and having them really go and take this head-on and be really hard working in trying to change the course of where they've been. So I think it's that kind of leadership that's going to help change that culture, but it has to be constant and driven around patient safety. []

SENATOR HARMS: Thank you. Thank you, Mr. Chairman. []

SENATOR LATHROP: We have been joined by Senator Abbie Cornett, who has questions so we'll... []

JOANN SCHAEFER: Morning. []

SENATOR CORNETT: Thank you very much for coming today, Dr. Schaefer. When you have done the surveys and you've gotten the reports back from the federal government and they've cited deficiencies over and over again, the same deficiencies,... []

JOANN SCHAEFER: Uh-huh. []

SENATOR CORNETT: ...what have you done or what has been done to correct these when it's the same type of offense over and over again? []

JOANN SCHAEFER: Sure. Well, and sometimes it's not uncommon to see the same sort of deficiency found each time. You know, we go through with a plan of correction. We try to make sure, when we go out back on the revisit, that they're up to speed and they're following everything in the plan of correction. And then really, you know, after that it's based on complaints and revisiting and their annual surveys, and they have to keep up that behavior to keep them from doing the deficiency again. []

SENATOR CORNETT: But what happens if the deficiency is found again and again? []

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JOANN SCHAEFER: Well, I think at that point, you know, this is not the only facility in the state that we've had problems with multiple deficiencies in the same area. You know, you really have to hold them to their plan of correction and changing that. I mean, it gets down to the point where you take a censure on their license and you do disciplinary action and those kind of things. But, you know, the goal is to get them to come into compliance with the regulations and understand what it is that they're not doing that gets them into trouble. []

SENATOR CORNETT: When you mention censuring on their license with some of the repeated deficiencies, have any of the professional licenses been revoked at the facilities? []

JOANN SCHAEFER: You know, I believe there have been some licensure actions taken place, but I don't have them and I could find that out for you. []

SENATOR CORNETT: Okay. What would the process be for that? []

JOANN SCHAEFER: For a professional license, they go into our Investigations Department, and our Investigations personnel go out and do a complete investigation on what was reported and then that license, that individual's license, action is taken against it. That then goes to the board of what...if they're a nurse then it goes to the Board of Nursing. Board of Nursing and the assistant attorney generals that work with the board come up with charges that may or may not be something that is filed. If they file the charges then it goes forward and the licensee has the opportunity to either work with an agreed settlement, where they come into compliance and agree to some censure on their license or a financial penalty. If they don't like the charges that are there and they don't want to go to agreed settlement, they have a contested case hearing. Those hearings are then heard and then the...it comes to me and I make the final decision on what the discipline should be for the person, which can include

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revocation, suspension, suspension with taking courses and training, civil penalties. There's a large array of penalties that can be levied on a license. []

SENATOR CORNETT: Okay. Thank you. []

SENATOR LATHROP: Senator Gay. []

SENATOR GAY: Just following up Senator Cornett's question, is...so when it goes to the board, you find deficiencies--she asked the same questions going through my head--how are they corrected then? Then it goes to a board, right? Who's on that board? []

JOANN SCHAEFER: Well, it depends on if you're talking about the individual, a nurse, did something, then it's the Board of Nursing that would go right on that nurse about that case. []

SENATOR GAY: On her nursing license. Okay, let's... []

JOANN SCHAEFER: Yeah, not on the survey in general. []

SENATOR GAY: ...let's put it this way. Let's say it's a general deficiency... []

JOANN SCHAEFER: Sure. []

SENATOR GAY: ...on how the operation is being run. You've been down there and we're talking about a ship going off course over ten years. []

JOANN SCHAEFER: Uh-huh. []

SENATOR GAY: And let's say three years in a row you got the same deficiency and you

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want to say, hey, no longer, we're going to do this, we're going to write you up or do whatever, but does it go to a board... []

JOANN SCHAEFER: No. []

SENATOR GAY: ...before you see it? It goes directly to you? []

JOANN SCHAEFER: Yeah. No, it comes to...it comes to us and we review it and then... []

SENATOR GAY: But when you say it comes to us, who is... []

JOANN SCHAEFER: To our division. So... []

SENATOR GAY: Okay. []

JOANN SCHAEFER: ...so the surveyors and Helen and myself and, you know. []

SENATOR GAY: At that point, though, here's where I kind of...I know we have a wall there... []

JOANN SCHAEFER: Sure. []

SENATOR GAY: ...and all the states are doing it this way, but at that point is...you guys are looking at this, there's no other input from outside sources, parents, there's no other review board. And I'm not big into creating new boards, but at some point, I mean, you know, we all have a boss kind of. That would be a hard decision to make. If you've got facilities around the state and you say, hey, we're going to shut you down, that's tough for anyone to make,... []

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JOANN SCHAEFER: Sure. []

SENATOR GAY: ...especially when you...you know. So what I'm saying is should there be something in-between there that says, hey, as a group. Maybe it includes a department or Health and Human Services Committee members. I don't know what it would include, but some providers, an independent review board that may look at this before it gets to you. I mean that's a tough decision for someone to make financially and pressure and everything else. []

JOANN SCHAEFER: Sure. []

SENATOR GAY: I just wondered if there should be something in between. []

JOANN SCHAEFER: You know, I've never thought of that. I would have to think about that for a little while, to be honest, but... []

SENATOR GAY: Because somehow things weren't being corrected over the course of time and I think there's plenty of blame to go around. []

JOANN SCHAEFER: Sure. []

SENATOR GAY: I don't think we could say it's this person's fault. []

JOANN SCHAEFER: Sure. []

SENATOR GAY: I think over the course of time, as people change, and that's just what's happened. But what we're looking at in the future, maybe how can we correct that so we do have the best facility? Because I, you know, we've all heard, oh, we used to be the leader, the best in the country,... []

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JOANN SCHAEFER: Uh-huh. []

SENATOR GAY: ...and obviously we're not now. I think we could be again, but maybe in the future we look at ways to say, you know, what can we do to be the best. But I just think that would be a tough decision for you to make. []

JOANN SCHAEFER: Well, it depends on the deficiencies that are cited, again, in what it is that we have found and how egregious it is. If it gets to the point where we have to take action on a facility and close them or restrict them in any sort of way, we have done that before... []

SENATOR GAY: Where at? []

JOANN SCHAEFER: ...not...I couldn't tell you offhand but I could...I can find it. []

SENATOR GAY: Very few times though. []

JOANN SCHAEFER: I can find those for you. But, you know, we want to give them the change to comply with regulations. And then if you go back and you see that they're complying, that doesn't prevent the next thing that can happen. And sometimes something bad will happen but the facility did everything correctly that they were supposed to do. And so, yes, something bad happened, but they followed their process perfectly. And so we don't find issue with that, but it is noted that something bad happened. []

SENATOR GAY: So you can't...and I understand you can't see into the future and say, oh gee. You can only correct it after it's happened, I understand that. []

JOANN SCHAEFER: Right. []

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SENATOR GAY: But I'm just saying, I don't care if it's Beatrice or any of these facilities,... []

JOANN SCHAEFER: Sure. []

SENATOR GAY: ...that's a tough decision because you've got clients there, I know, you know, wherever it is. []

JOANN SCHAEFER: Oh absolutely. []

SENATOR GAY: So maybe there's some kind of other barrier or review panel or something we could set up between...and I don't know what it is today but I just...I think that's a tough decision for even if you weren't in that position. Whoever is sitting in your position five years from now, it's going to be tough, but maybe they could use a little help like we do on a 407 review or something like that, a bigger group. I don't know. It's something we could talk about maybe later. []

JOANN SCHAEFER: Sure. Be happy to. []

SENATOR LATHROP: Maybe to follow up on Senator Gay's question, ultimately, you can't vary from the standards because CMS is the ultimate arbiter of what's right... []

JOANN SCHAEFER: Right. []

SENATOR LATHROP: ...and what's wrong... []

JOANN SCHAEFER: Right. []

SENATOR LATHROP: ...and so all you're doing is taking their standards and interpreting them and applying... []

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JOANN SCHAEFER: Right. []

SENATOR LATHROP: ...them to the care that you're seeing on your surveys, right? []

JOANN SCHAEFER: That's correct. And then they will levy... []

SENATOR LATHROP: So if they're violating them, you write them up just like CMS tells you how to do it. []

JOANN SCHAEFER: That's right. And CMS has, you know, the ultimate, you know, you know, stopping their funding as a tool, you know, that is used frequently. []

SENATOR LATHROP: Okay. Senator Wallman. []

SENATOR WALLMAN: Yeah, thank you, Chairman. Thank you for being here. Sorry I'm a little late. As far as the gravity of these offenses, you know, these complaints, is that...I hate to see that, you know, and I think everybody does. Do they... []

JOANN SCHAEFER: Uh-huh. []

SENATOR WALLMAN: ...are they against specific individuals, as a rule? Do you check into that? Is it, you know, is it verbal abuse? Is it sexual abuse or physical abuse? []

JOANN SCHAEFER: It could be anything that we get a complaint on and then... []

SENATOR WALLMAN: And is it against...do they take into account if it's against one person, you know, one resident, if they happen to embellish the truth, or do they keep track of that also? []

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JOANN SCHAEFER: I guess I'm not quite sure I understand your question. If there's a complaint... []

SENATOR WALLMAN: Well, just say that I'm the person. []

JOANN SCHAEFER: Okay. []

SENATOR WALLMAN: You know, I don't like you as my caretaker. []

JOANN SCHAEFER: Okay. []

SENATOR WALLMAN: And I say you abused me this morning or something, and I scratch myself. And if this person does that over and over again to somebody, is that taken into account? []

JOANN SCHAEFER: Yes, we do take that into account. []

SENATOR WALLMAN: Okay. Thank you. []

JOANN SCHAEFER: And we try to be as savvy as possible on those difficult cases. []

SENATOR LATHROP: Senator Cornett. []

SENATOR CORNETT: When...you said that you followed CMS's guidelines, correct? []

JOANN SCHAEFER: Yes. []

SENATOR CORNETT: And that the ultimate threat was the revocation of funding from CMS. []

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JOANN SCHAEFER: Sure. []

SENATOR CORNETT: You also stated that there had been facilities closed before in the state? []

JOANN SCHAEFER: Or put...not... []

SENATOR CORNETT: Maybe not under your direction but... []

JOANN SCHAEFER: Yeah, I know we've done some suspensions and we've done some...the payment issue is usually the thing that brings them around and is pretty swift, if they cannot come into compliance with their plan of correction. []

SENATOR CORNETT: Were those measures looked at, at Beatrice? Since we are in a situation where we're facing losing federal funding and obviously the situation was that grievous, how come the state hadn't stepped in and done something before that? []

JOANN SCHAEFER: Well, I think that that's exactly what was done, is that we have found deficiencies. They had come in to do a deficiency look and it got to that point. Plans...opportunities for plans of correction were given. They couldn't meet the conditions of participation and that's when, you know, the case went that way. So that... []

SENATOR CORNETT: You didn't need to look at shutting it down as a state because you felt the federal government would? []

JOANN SCHAEFER: And...well, we didn't find this...no, we didn't find the same amount of deficiencies or the type that they found when they sent in their large team. []

SENATOR CORNETT: That's what I was getting...now do your survey teams work

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together at the same time? Do you send in survey teams at different times? And why is there such a discrepancy between what you found and what they found? []

JOANN SCHAEFER: Sure. Well, we send in two for maybe a week or however long it takes to fill out the entire survey, do the entire survey process, everything that we're supposed to do on it. They sent in, I believe, 11 people for two weeks. So there's already, there, you're going to set up a huge discrepancy in what they can find. If you put that many people in a facility, will find multiple things because you've a longer time to observe them. When our folks are there for a lesser time, they may not see all that there is to see that is bad, per se, even though they're completing the full survey process. []

SENATOR CORNETT: That brings up another question. When you have limited resources, when you're talking about two people for a week or... []

JOANN SCHAEFER: That was just an example. []

SENATOR CORNETT: ...that you send in, and there is the thought that maybe moving to community-based services would be the direction we should move for some of the patients, if we can't provide the staffing to oversight our own facility, how are we going to provide the proper level of oversight in community-based? []

JOANN SCHAEFER: Well, we're doing some community-based now, which Helen is going to explain how we do that now and, you know, that's going to be a challenge for us. But, you know, CMS funds us to do the work that we're told to do and that's what we...we do with what we have. []

SENATOR CORNETT: Do you see that you will be able to supervise or provide the proper level of oversight in community-based since we're already having a difficult time doing it at our own facilities? []

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JOANN SCHAEFER: Sure, I see your point in that. You know, we have a lot of community-based providers right now that we're already doing that process. If there's a huge number the come on board, that all of a sudden start providing new services, get licensed and, you know, that could change the dynamic very much and we may have to look at things. But at this point we're doing some community-based, in fact many community-based, surveys and follow though. So one would hope that we'd keep up. []

SENATOR CORNETT: Thank you. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: Thank you, Senator Lathrop. Dr. Schaefer, in our earlier conversation that we were having, you indicated that Beatrice just slowly over time moved off course. How do we prevent that from ever happening again? I mean that really, to me, is the heart of the issue. []

JOANN SCHAEFER: Yeah. []

SENATOR HARMS: How could we actually start that from occurring, and what do we have to put in place to never allow that to happen again in this great state? I mean, that's really what this issue is all about. []

JOANN SCHAEFER: Absolutely. []

SENATOR HARMS: No matter what we find and no matter what the recommendations will be, we still have to think about the future, making sure that we don't have to do this kind of conversation again, you know, in the next five or ten years. And so what would your recommendation be? []

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JOANN SCHAEFER: You know, they've made a lot of changes right now in their leadership down there and I would hope that that would start to, you know, really change things, in fact it already has, so, you know, strong leadership, strong management and very well-trained staff that have a clear eye on what the mission is of BSDC. []

SENATOR HARMS: So in that process, would your role change any to make sure that we're not drifting aside? And if it is then what would you do to start to correct that? []

JOANN SCHAEFER: Well, it could. That would be something separate, an addition that the state would ask us to do. It would be kind of above and beyond what CMS expects us to do, so it really would be up to your discretion as to what you saw our future role is doing anything on or above that. []

SENATOR HARMS: In regard to our community-based programs, as you look at our community-based programs as we have today, are we prepared to move more patients out of that center into community-based programs? []

JOANN SCHAEFER: I think it depends on the patient and the setting that they're going to. It's got to be a good fit for both of them and I think there are a lot of great places out there that do fantastic community-based services. []

SENATOR HARMS: Do we have the system established to be able to do that, to be able to monitor that, to be able to supervise that? Because my greatest fear would be,...

[]

JOANN SCHAEFER: Sure. []

SENATOR HARMS: ...as we make this transfer, we could get ourselves into a much more difficult situation than we have today because we have no...we may not have the

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right staffing to monitor. What are your view about that? []

JOANN SCHAEFER: Well, of course I have concerns. We are doing a lot of monitoring already in the community-based services area so, you know, we would continue to do that. []

SENATOR HARMS: So your concerns center around what points? []

JOANN SCHAEFER: Having enough people to get in to review complaints if complaints went up dramatically. In fact, that's something that is of concern but we have no reason to suspect that will change. We have a long number of years of watching and being able to keep up, but I'm sure there are concerns there because that's where you get at the heart of what's happening in a place when a complaint is filed by anybody about the care of either their loved one, their friend is receiving at a place. []

SENATOR HARMS: Thank you. []

SENATOR LATHROP: Doctor, now I have some questions. []

JOANN SCHAEFER: (Laugh) Okay. []

SENATOR LATHROP: It sounds like you're telling us that in the community-based programs they're complaint driven, primarily,... []

JOANN SCHAEFER: They get surveys too. []

SENATOR LATHROP: ...and that's where you get to the bottom of it. So we have in many instances people that can't communicate at all and we're waiting for a complaint to come in before we can do an inspection to kind of get to the bottom of whether or not some provider in some part of the state is doing a good job, a poor job or whether we

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have a systemic problem within an institution that we don't randomly survey. That... []

JOANN SCHAEFER: Sure. We also have random surveys of the community-based as well. []

SENATOR LATHROP: And that's kind of the other question. I put...I had the page put in front of you a document that we...that I think it came from your office, didn't it? Do you recognize that? []

JOANN SCHAEFER: (Exhibit 2) Yeah, I believe so. I think Helen put this together. Yeah. []

SENATOR LATHROP: Do you see it? It says DHHS,... []

JOANN SCHAEFER: Uh-huh. []

SENATOR LATHROP: ...Division of Public Health. That's your office? []

JOANN SCHAEFER: Yep. []

SENATOR LATHROP: And the line below that is, "Information on On-site Visits to Entities Serving Persons with Developmental Disabilities." That would be sort of a tally of the inspections made in 2006, 2007, and so far in 2008 to the various institutions that provide services to people with developmental disabilities. Would that be the case? []

JOANN SCHAEFER: Uh-huh. Yes. []

SENATOR LATHROP: And if we look at it, it breaks it down into three categories. One is ICF-MRs, which would include Beatrice. And Mosaic also runs three ICF/MRs. Is that right? []

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JOANN SCHAEFER: That's right. []

SENATOR LATHROP: That's intermediate care facilities. That's what the... []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: ...that's what that stands for? []

JOANN SCHAEFER: Uh-huh. []

SENATOR LATHROP: Okay. The next category is CDDs. What's CDDs? []

JOANN SCHAEFER: Centers for developmentally disabled. []

SENATOR LATHROP: Pardon me? []

JOANN SCHAEFER: Centers for developmentally disabled. []

SENATOR LATHROP: Can you give me an example of that? []

JOANN SCHAEFER: Well, actually, that's what Helen was going to do the whole explanation of that. She has quite a bit to say. It's a step down and it's a limited number of individuals that are taken care of at those sites. []

SENATOR LATHROP: Are those high-need people, or is this the Bridges Program or... []

JOANN SCHAEFER: They're not as high need and, yes, Bridges is in there. []

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SENATOR LATHROP: Okay. And then the last one is DD HCBW Providers. []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: What's that...? []

JOANN SCHAEFER: That's home- and community-based waiver providers. So they are slightly different and, again, Helen has the finite details of what makes them different, but these are Medicaid eligible providers for paying. []

SENATOR LATHROP: Okay. In the rundown or in the summary we have, under the ICF/MRs, we have an annual survey for each institution, and there are four of them. We have a category for annual survey, a category for complaint investigation, and a category for revisit. Is that right? []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: And then that's true with all four of the ICF/MRs. []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: And then we go down to the community-based providers, which is the third category, and we don't have a category for annual survey. Do you see that? []

JOANN SCHAEFER: Uh-huh. []

SENATOR LATHROP: We have a category for complaint investigation and for revisit, where you identify the number of those that your office undertook in each of the three years that are represented in this document,... []

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JOANN SCHAEFER: Uh-huh. []

SENATOR LATHROP: ...but nothing in there for annual survey. So my question is, are we doing annual surveys on folks that are community-based providers? []

SENATOR LATHROP: Sure. And I need to ask Helen one technical question about that. Is that on random selected group (inaudible)? []

HELEN MEEKS: For CDDs. []

JOANN SCHAEFER: For CDDs, the percentage. []

HELEN MEEKS: They're randomly selected up to 25 percent. []

JOANN SCHAEFER: It's up to 25 percent for the annual survey on the CDDs, so they are done but they're not done on all of them. So every four years one would be. []

SENATOR LATHROP: Okay. So if I am a community-based provider in any part of the state of Nebraska, you're going to do a survey or an inspection of my operation once every four years. []

JOANN SCHAEFER: Sure. Yes. []

SENATOR LATHROP: And absent a complaint from one of my patients or residents or clients or a family member, I'm just going to...I'm not going to see or hear from the state at all. []

JOANN SCHAEFER: Possibly, yeah, absent a complaint. []

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SENATOR LATHROP: Does the...does...we know that CMS has certain requirements for Beatrice State Development Center. That's why we're here. Do they also have similar oversight of Mosaic at Axtell and Beatrice and Tri-City? []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: The other ICF/MRs? []

JOANN SCHAEFER: Yep, exactly the same. []

SENATOR LATHROP: Are they getting written up in the other ICF/MRs? []

JOANN SCHAEFER: Yes. Yes, they are. []

SENATOR LATHROP: Does the...do the...what do they call it when they find something wrong? []

JOANN SCHAEFER: Deficiencies? []

SENATOR LATHROP: Deficiency, that's the term they use. []

JOANN SCHAEFER: Uh-huh. []

SENATOR LATHROP: What's the...are the deficiencies at, for example, any of the Mosaic institutions, do they rival what's going on at Beatrice? []

JOANN SCHAEFER: There are similar similarities, yes, in some of them. []

SENATOR LATHROP: And when we talk about community-based programs, that would include those ICF/MRs that are run by Mosaic? []

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JOANN SCHAEFER: No, those would not...those are not community-based. []

SENATOR LATHROP: Okay. They're just institutions that are privately run. []

JOANN SCHAEFER: They are an institution like...yes. Exactly. []

SENATOR LATHROP: How many people do you have...pardon me. Let me back up. Does CMS have any say in how often or what your inspections or your surveys look like... []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: ...of the community-based providers? []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: And they're okay with you going out once every four years? []

JOANN SCHAEFER: That's what their plan is. []

SENATOR LATHROP: Okay. So you're doing... []

JOANN SCHAEFER: What they ask us to. []

SENATOR LATHROP: ...what they've asked and that amounts to once every four years.
[]

JOANN SCHAEFER: Yes. []

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SENATOR LATHROP: By contrast at Beatrice, somebody was there, either you or CMS, at least once a year. []

JOANN SCHAEFER: Right, in all of the ICF/MRs. []

SENATOR LATHROP: How many people do you have that work for you, surveyors or inspectors, that are actually available to go and inspect all of the institutions that we see listed on this chart? []

JOANN SCHAEFER: Helen, what is our current number? Four. []

SENATOR LATHROP: Four? How many institutions or community-based providers are there represented on this? This is all of them, right? []

JOANN SCHAEFER: Yes. []

SENATOR LATHROP: How many are we talking about that these four people get around or are responsible for inspecting? []

JOANN SCHAEFER: The number of places? []

SENATOR LATHROP: Yeah. []

JOANN SCHAEFER: Do you have that? []

HELEN MEEKS: I can give you the total numbers. []

JOANN SCHAEFER: She has the total numbers written in her testimony. []

SENATOR LATHROP: Okay. Okay. []

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JOANN SCHAEFER: I don't have it offhand. []

SENATOR LATHROP: I think that's all I have. []

JOANN SCHAEFER: Okay. []

SENATOR LATHROP: Senator Cornett. []

SENATOR CORNETT: Dr. Schaefer, can you explain to me why there would be a difference in inspection requirements or the survey requirements between a state facility and a community-based facility? If we're there every year and frequently more than that, why is it acceptable that we only inspect the community-based or survey a community-based provider every four years? []

JOANN SCHAEFER: You know, I don't know why that's deemed acceptable. That is what we're asked to do and that's what we are given the resources to do. []

SENATOR CORNETT: Do you personally find that acceptable? []

JOANN SCHAEFER: You know, having taken care of a lot of children in my practice that lived in CDDs, there are a lot of really good CDDs out there and... []

SENATOR CORNETT: But are there bad ones? []

JOANN SCHAEFER: And, yeah, you have your bad eggs, so to speak, in every bunch. But there are a lot of places that are doing a really good job. And just as a physician, I had the opportunity to report anything I found deficient at any time at those places because I was seeing the patient that would come in to me. So if their medications weren't right, if their nutrition didn't look good, if there was something, they had bruises

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or something that couldn't be explained with their caretaker, that that's another opportunity that we...you know, the medical community helps us with some of that oversight, too, because they see these clients. []

SENATOR CORNETT: Okay. The question, though, was do you think every four years is adequate? []

JOANN SCHAEFER: You know, if we wanted to make it all fair then everyone should do it once a year, but I don't, you know, the resources for that and whether it would actually provide you with any increase in safety, I don't have an answer for that. I don't have any data that tells me that that's more effective or a better use. []

SENATOR CORNETT: Moving back to some...the line of question that Senator Harms was going at, it brought up to mind a couple of things. Could you describe to the committee the special needs of people at Beatrice and why they are there currently rather than a community-based, and whether you feel that moving towards community-based for all the residents is possible. []

JOANN SCHAEFER: Well, it's probably not possible for all residents, since, as we see, that's why we have Mosaic having three ICF/MRs themselves. They are higher needs patients, in general, or clients, in general, but not all of them. The point of having an institution that does that is that you can provide ongoing rehab services and bring all the services in there for the client so they're all there on one site. In the community it's very appropriate or some folks to live in a small group home and be able to attend services, get the services they need outside of that area, but that's very patient specific. []

SENATOR CORNETT: Moving on, how does your reporting process work from your office to John Wyvill and to Chris Peterson? Do you meet with them directly? Do you file reports with them? How is your reporting process? []

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JOANN SCHAEFER: We work with them just like we would any of the Mosaic ICF/MRs. We would send them the letter regarding the deficiencies or the report or whatever we found, whatever an issue is, and then they have an opportunity, just like anyone else in the public has an opportunity who runs a facility, to come in and speak to us about corrective action plans, what needs to be done, and that's how it works. We don't go down the hallway and have a casual meeting. It's all done in the same formal way. []

SENATOR CORNETT: So all of your surveys, your reports, your recommendations are done in a formal process with Health and Human Services. []

JOANN SCHAEFER: Yes, just as they are with Mosaic. []

SENATOR CORNETT: And these are filed, written reports. []

JOANN SCHAEFER: Uh-huh. []

SENATOR CORNETT: And who else has access to those reports? []

JOANN SCHAEFER: You can request copies of your surveys and then they're ours, and we've given you ten years worth. []

SENATOR CORNETT: Okay. Thank you. []

SENATOR LATHROP: Senator Wallman. []

SENATOR WALLMAN: Thank you, Chairman Lathrop. Doctor, I'm not against community-based care. I want you to know that. Our daughter runs one in Iowa and she does her own inspections. And she asked neighbors, it's kind of like a foster parent. So we do not have the staff to do that, I don't think. And she finds abuses and they're fired immediately and no suspensions. They're gone. So do we as a state have that ability to

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do that? And some of the clients, she's went to BSDC and talked to them, and those clients there, you probably won't find private care providers for a lot of them, and she told me this. I asked her. And so what are we going to do then? We'll probably put them in a worse situation than they're in. []

JOANN SCHAEFER: Absolutely. If they're not in the right level of service that they need then you don't do...that's why it has to be very patient-focused and... []

SENATOR WALLMAN: Thank you. []

SENATOR LATHROP: Yeah. []

SENATOR CORNETT: Dr. Meeks... []

SENATOR LATHROP: Oh, go ahead, Senator Cornett. []

SENATOR CORNETT: I'm sorry. You were talking, sorry. At previous hearings the question, and it was a question I brought up, do we have the community-based services available to meet the needs, and the response was that as the need for community-based service grows then the businesses will grow with them. []

JOANN SCHAEFER: Uh-huh. []

SENATOR CORNETT: Do you feel that the state of Nebraska is adequate currently in the amount of community-based services available? []

JOANN SCHAEFER: You know, I don't know the numbers cold. I've heard the same responses to my questions about the same, that as the...as... []

SENATOR CORNETT: Need grows the... []

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JOANN SCHAEFER: ...the need grows, the services will grow with them. There's certainly a lot of people out there that want to help and be in this line of business. []

SENATOR CORNETT: Do you find any shortage though currently of community-based services? []

JOANN SCHAEFER: We haven't been faced with a situation where we've found a shortage anywhere in trying to find, no. []

SENATOR LATHROP: That's really not your... []

JOANN SCHAEFER: No. []

SENATOR LATHROP: ...in your wheelhouse, though, it is? []

JOANN SCHAEFER: That's right. []

SENATOR LATHROP: I mean, your job is to make...to do the inspections and not to decide whether we have enough capacity. []

JOANN SCHAEFER: That's right. It becomes a little bit of an issue on the nursing home side, When nursing homes close then we try, you know, to protect each client, make sure that each client is taken care of in coordination with the business or when there's a shift of ownership or what have you. []

SENATOR LATHROP: I think that's it. []

JOANN SCHAEFER: Okay. Thank you. []

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SENATOR LATHROP: Thank you for your testimony. We appreciate that. []

HELEN MEEKS: Good morning. May I start? []

SENATOR LATHROP: Welcome. Sure. []

HELEN MEEKS: (Exhibit 3) Okay. I'm Helen Meeks and my last name is spelled M-e-e-k-s, and I'm the administrator for the Licensure Unit within the Division of Public Health, Department of Health and Human Services. And my testimony is going to focus on how we regulate or inspect settings that serve persons with developmental disabilities and...go ahead. []

SENATOR LATHROP: Yeah, I was going to ask if you can tell us a little bit about yourself professionally before you tell us about your testimony, because we really are fortunate to have somebody with your background and your reputation here at the state of Nebraska. []

HELEN MEEKS: Well, thank you. Thank you. []

SENATOR LATHROP: Maybe you can share that with the other members of the commission. []

HELEN MEEKS: I've work in Nebraska state government for about 33 years and my professional training is in speech and language pathology. I am a graduate of the University of Nebraska, a master's degree in speech pathology. My undergraduate degree is in speech communication from Jackson State University, and I always say that's the school that Walter Payton attended, so people will know that. And I've been in Nebraska for 30-plus years and love it. It's home for me now. We have a history in terms of the regulatory activity for various entities. The Licensure Unit, we have four major programs in our unit. One is the licensing and certification of healthcare facilities,

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and many of your questions, we can talk about some of that. We also license all of the people. If you have to have a license or certification, registration to do anything that's health or health related, we administer the licensing activities for those groups. We also license all the childcare programs, and then we do certificate of need. So those are our four major programs within the Licensure Unit. And we have people around 157 employees, and they're spread all across the state. We inspect, as an example, all the pharmacies and so I have a pharmacy inspector that is out in the Cozad area who goes west, and we have one in Omaha area who does the eastern part of the state. So many of our surveyors, the people who survey the hospitals, the nursing homes, the ICF/MRs, they're spread all over the state and they report to managers who are located within our central office. In terms of regulating settings that care for persons with developmental disabilities, we are authorized by primarily two things. One is state statute and that's the Health Care Facility Licensure Act, and it's codified in Chapter 71, starting with section 401. That grants the authority for the state to license BSDC, Mosaic or the hospitals in this state, and that statute sets out certain regulatory authority. Now it's primarily the only reason we license anything as a healthcare facility or service is for protecting the health, safety and welfare of the persons who are going to be served there. That's our statutory authority to do that. The second level of authority that we have for regulating Beatrice State Developmental Center and other settings is through what is known as the 1864 agreement--I often say I don't know if it was done in 1864; I certainly was not around if that's the year that that agreement was started--but that's an agreement with the Centers for Medicare and Medicaid Services, or CMS. They contract with various state agencies to do what is referred to, or what they refer to, as survey and certification activities, and the only reason, the only reason that a facility would be under the egis of CMS is if they wanted money, if they wanted to receive Medicare or Medicaid funding. BSDC, as an example, is funded through Medicaid and that's why we survey them in that regard. They have to be licensed first, as your question talked about. That's their ticket, I often say, to operate. The state of Nebraska says in order to be a hospital you have to have a license, and there are certain requirements that they have to meet, and we look at those prior to the time that we would issue a license and then there are some

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inspections that go on after they become licensed. In terms of ICF/MRs in this state, we have...in terms of services or settings, I should say, that care for persons with developmental disabilities, there are three types of settings. One is the ICF/MRs, another one is the CDDs or the centers or group homes, and then the other one is the home- and community-based waiver settings or programs. Now an ICF/MR is defined in state statute as well as in CMS's statutes...regulations as a facility where a number of things occur: shelter, food, training or habilitative services, advice/counseling--the list goes on and on--diagnosis, treatment, care, nursing services, dietary services. All of the things that the people who are residing in that facility needs the ICF/MR is to provide it and the statute defines them as if you are providing those services for 24 consecutive hours to four or more persons. That's what an ICF/MR does. And the persons have to have...who are...who have mental retardation or related conditions. And our state statute goes on to say some of those related conditions: epilepsy, cerebral palsy and/or other things that affect one's development. That's what an ICF/MR is defined in state statute as being. Now our statutes do not restrict the size, the upper limits or the maximum size of an ICF/MR facility. However, under our state Medicaid regulations for the state of Nebraska--these are done within...by the Medicaid and Long-Term Care Division within Department of Health and Human Services--there is a minimum of 15 persons that is set under state regulations. An ICF/MR can be as large as it wants to, but it has to be at least, if you're going to participate in Medicaid, 15. Now there are four ICF/MRs in our state and we've talked about those. BSDC, and BSDC has a license capacity of 404. Doesn't mean that they have that many residents at any given time. When we go in to survey a facility, we look at the size, the infrastructure that they have in place, including the staff, their procedures, all of the things, could they care for up to that maximum capacity. And once we make a determination then that's usually how they set their licensure. But again, their census can be anything more than that. Mosaic in Beatrice has a capacity of 140, Mosaic at Axtell has a capacity of 112, and Mosaic Tri-City, which is located in Grand Island, has a capacity of 9. Now you just heard me say that under state Medicaid regulations the minimum is 15. This facility was in operation prior to the time that our Medicaid Division put that minimum of 15 there and

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so they grandfathered that facility in. So it's nine and that's why that number is there. In terms of the centers for developmentally disabled, or CDDs, these are...again, they...when you look at the statutory definition, they pretty much can do or care for people with the same needs as an ICF/MR, but it has to be four or more, and we have many of our settings, and when you were talking about community programs, many of the community...things that are in the community, a group home or an apartment or a condominium, many of them only have three people and so those places do not have to be licensed by our state statute so we would not be in there looking at them from a licensure standpoint if they had fewer than four. However, if they are receiving any funding through Medicaid, as an example, or through their home- and community-based waiver program, then there are requirements that they have to meet and we would survey or inspect them in relationship to those requirements. The CDDs tend to provide services to clients who have fewer needs, particularly physical health needs, because...and that's their choice. They are just designed...they are not, as Dr. Schaefer talked about, some community settings will, if the person can be able to get, you know, medical services or whatever by going to their doctor, their physician, like you and I do, they could probably live very well in a group home. If you have a person whose physical health needs, as an example, require skilled nursing on a 24-hour-a-day basis, those people tend to live and be cared for in an ICF/MR setting, just because it makes, I guess, more sense economically to do so. In terms of CDDs, there are 155 CDDs in our state and they have a licensed bed capacity of about 872. So in those kinds of settings we could care for 872 people statewide. If there were more that came on board, obviously we would inspect them to determine if they meet the licensing requirements. Again, CDDs typically, there's no restriction, a CDD could be as large as BSDC if they chose to do that because there's nothing in state statute that would restrict them or limit them. But they tend to limit themselves to four or six beds and usually I think that's just because of the way they choose to set up their service. And again, in addition to being licensed, CDDs typically are certified to receive funding under the home- and community-based waiver program. And again, we're not...we may not necessarily be able to explain all of these different funding streams and so forth. That's not our

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responsibility within the Division of Public Health. We serve as the entity that surveys and inspects them. I think all of our CDDs, as an example, maybe with the exception of one, and I can't remember where that one is located, also have home- and community-based waiver clients who receive funding through the home- and community-based waiver, and that's allowable. The home- and community-based waiver providers provide services to adults and children with mental retardation and related services, and again, they must be certified in order to...for the individuals they serve to receive this funding through Medicaid. And evidently there were some federal dollars that came about in our state through our Medicaid, and Long-Term Care Division applied for this, what is called the waiver funding, and so I guess there's quite a bit of money that comes into the state of Nebraska through this funding stream and we have community-based providers that get the benefit of that funding. Right now there are 31 home- and community-based providers in the state, and some of them may be here today to testify later, and they have 1,460 settings. So, as an example, Region V is a provider and in Region V you might have 300, 200, or 100 settings, and so that's how they work. When we go out and inspect them, if we're looking at Region V, as an example, as the provider, we can go into any of the settings in Region V. We just wouldn't go to one setting if we are there doing our routine inspection. We would choose several settings. One setting may be residential, or the only services that they are providing would be residential, teaching people or caring for people in terms of, you know, how to take care of themselves, personal needs and those kinds of things. We also may look at their...if the people...some regions have day treatment programs where folks go to a workshop or they go to other jobs, and we would look at the systems that they have in place as it relates to job training and so forth for those individuals. So we would be looking at various components or aspects of the services that a provider has and that would occur during the inspection. Since the department, at that time the state Department of Health, was already designated as the survey agency, when the home- and community-based program came about it was designated, the state determined back in 1987, that we, the arm of the agency that serves as the public health entity, would also inspect these home- and community-based waiver settings. The regulations,

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though, are set by the state. They're set under the authority of the Medicaid Division, not by CMS, in terms of home- and community-based waiver programs. So that is one of the distinctions, and the state has a lot of leeway in terms of what they include in those regulations. So usually there's a joint effort in terms of the regulations development for the home- and community-based waiver. Medicaid, Mr. Wyvill's division, and then Public Health would typically be at the table working on these regulations and those would be the ones that we use to inspect the home- and community-based providers. They provide, again, home- and community-based waiver settings provide usually three types of services: residential, what we call day treatment or what's referred to in the regulations as day treatment, and then respite services, and that's basically where you have a program set up or designed to give the caregiver a break, as I like to call it. If the person is living at home, parents are taking care of him or an older sibling or younger sibling, for that matter, the state, I believe through the waiver program, pays for respite services for people to come in and give the regular caregiver or provider, or respite services that may be occurring in a freestanding facility. The regulatory process that we use for ICF/MRs--and we've talked about this, you've asked a number of questions--under federal rules for participating in Medicaid as an ICF/MR, they must be surveyed annually, and their certification is tied to that annual survey. If they would not pass certification, as an example, if BSDC does not meet those conditions of participation, they would not be recertified and, therefore, they could not receive federal funding. There's a long, drawn out process that one has to go through before they're going to be decertified. We talked about that earlier. You go on site, you inspect them, and they, if there are deficiencies found, depending on the nature of the deficiencies, the facility sets up a plan of correction. The inspecting agency determines whether that plan of correction is acceptable. It might require a revisit or a follow-up visit to see are they implementing it and so forth. Before you're going to get to the point where funding would be in jeopardy, there are several steps involved. The ICF/MR annual surveys can be done by either the state, as we are doing now being the survey agency; however, CMS may choose to participate in the survey either with the state or they can conduct a survey independent of the state, which they did at BSDC in 2006. Prior to that time we

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had been conducting those surveys and since 2006 we have been conducting all of the complaint investigations at BSDC. I think we started that. CMS asked us to start doing complaint investigations, I believe it was in...last year. I know it was in 2007. So any complaints that have occurred at BSDC since then, we were in there doing those investigations. The surveys are extensive and they can range anywhere from one week to several weeks, depending on the size of facility, the number of surveyors that go in, and the nature of the survey findings once the survey starts. And we have four surveyors. CMS, as Dr. Schaefer pointed out, had brought in a larger number of surveyors when they went into BSDC in 2006. The surveys examine several areas. There are eight conditions of participation and those are listed in my testimony: governing body, client protections, facility staffing, active treatment services, client behaviors and facility practices, healthcare services, physical environment, and dietary services. Within each of those conditions there are many, many regulations and standards. I brought a little book and if you guys want this book you can keep it, because it lays out for under each condition here are the standards. Like under governing body, as an example, it may have one that you have to...one standard is you have to appoint someone who's in charge. Senator Harms asked about that. There has to be someone in charge of that facility and that person has to have certain responsibilities and those are specified in the regulations. We, their survey agency, do not run a facility. We don't go in there. That's not our job to go in there and do the administering and the day-to-day operation of the facility, whether it's a state-owned facility like BSDC or if it's BryanLGH Hospital. That's not our role to go in there and run that facility on a day-to-day basis. We survey for compliance with the eight conditions of participation and there are a lot of survey tasks that are involved. CMS dictates the protocol in very detailed fashion, however, there are three general methodologies that we use during survey: records review, observation, and interviews. Those are the general methodologies that are used. There's a random selection of clients that occurs when we walk into a facility and the selection is based upon the size. So the premise is the greater the census in the facility, the larger your sample is going to be. For instance, CMS's requirements is that if the facility census is between 17 and 50, you've got to

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look at 8 individuals and you have to look at those individuals in a very detailed fashion. If the facility is larger, like BSDC, where you have 100, if it's between 101 and 500 beds, we have...I think the sample selection, we're required to do a 10 percent sample and so, of course, you see the numbers would go up the larger the census would be. We would review the sample clients, review their care, their treatment, training records, medical records, incident reports. The individual program plans would be reviewed to determine what needs had been identified, whether the staff are meeting those needs. We would do observation of care of the sample clients. We...during the survey process, that observation can occur at any time, including early morning hours, evenings, weekends. Once a survey start, the surveyors, whether they are state people or the federal people, can be in that facility at any time and we can remain in that facility as long as possible, and that is so that you can get a depiction of what is actually happening. If you have a situation where there's a problem that relates to, say, the breakfast serving, then you have to be in there during the time that they're going to serve breakfast in order to do an adequate survey. You just can't show up and say we're going to be there for the noon meal and the evening meal, and do the observations then. In terms of interviewing, that includes interviews with all levels of staff, direct care staff, middle and upper management. We also interview clients, those that are cognitively capable of responding, as well as family members and/or guardians. And so, I mean, that gives you a general overview of the methodologies that are used: interviewing, observation, and records review. And I think the rest of my testimony we've touched on already in terms of sampling, procedures for records review, all of that specified and we would follow those procedures. I should point out, too, that at the time of the annual survey, we also would do...look at licensing things. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: Thank you, Senator Lathrop. Helen, thank you very much for your testimony. []

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HELEN MEEKS: Thank you. []

SENATOR HARMS: Listening to you in regard to all the rules and regulations that we have that really govern an institution like Beatrice, the thing that still bothers me, how could we allow ourselves to get into the situation that we're in now? What actually broke down to allow Beatrice to be in the position it is now? That's what really...that's what I keep groping with, I keep trying to penetrate to find out. What happened? []

HELEN MEEKS: I think... []

SENATOR HARMS: I mean with everything you've got right here, there should be no reason in the world that we're in the position that we're in today, so what actually happened? []

HELEN MEEKS: I think, Senator, there are a number of things that happened. First of all, Beatrice, BSDC, had not been deficiency free over the years. They had had deficiencies and so...but there's a process by which you can correct them. Now I think also you can have a change--and we don't just see this in an ICF/MR facility, we see it in a nursing home--you can have a change in administration and we normally will see, too, when you have, if your administrator...something goes awry, or your director of nursing, you can have a facility that can go downhill very, very quickly because of those kinds of changes. You know, I can't tell you and give you a this-is-exactly-what-happened act at BSDC. What I can tell you is that there were deficiencies that had been cited. They were given the opportunity to correct those deficiencies and they got back on course. And then you can steer back off course for a variety of reasons. []

SENATOR HARMS: Well, it seems to me, at least from my observation, that's all it is, is that somehow we don't have the check and balance system truly in place to correct what took place. If it happens that rapid, and I think this has been a slow process of

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occurring because of earlier conversation, it went off course and we were unable to bring it back. And I guess what I am trying to come to grips in my mind, how do we stop that from ever happening again? I mean you have policies, you have the rules, we have the regulations. But, in my mind, something broke down and we should have had the brakes put on this much quicker because we're...I think we're putting people at risk and that families place their loved ones there and that we have the responsibility to make sure that they have the best care possible, and it's clear in many cases that wasn't true. That didn't happen, and that's what I'm driving at. I mean how do we...how do we fix that? []

HELEN MEEKS: Well, I think certainly from a survey standpoint, you could say you're going to put in enough resources that we're in a facility every month, but I don't think the answer...I think it's a multiprong answer. The fix, I should say, is multiprong. I think it's regulatory piece, it may be more frequent oversight, more in-depth oversight. But it also has to be accountability within the operation all the way through the facility, and I think that's part of the fix. And we, as the regulatory piece of it, cannot assume and have not assumed the responsibility for it. So, in my mind, it's multiprong, that starts with the operation, the day-to-day operation of the facility, you touched on cultural change, holding people accountable for what's going on in those facilities, and that doesn't necessarily...it cannot solely rest with the regulatory piece of it, you know. []

SENATOR HARMS: It's clear to me that we didn't hold them accountable. We identified the issues, but they continued to...they continued to go astray. So in this process, when is it that it should be brought to another level and addressed at another level? Because it's clear that we didn't...to me, at least, it's clear that we did not have the appropriate leadership in that institution to correct this. So where is it in this process that we go to a next level that says, you know what, you have a very serious problem here and it needs to be corrected now? It seems like to me in this whole thing it just fell aside and I don't know if it was ignored, I hope it wasn't, but that's what my observations are. So when do we go to the next level and what process should be put in there so you can go to the

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next level to address the issue? []

HELEN MEEKS: Perhaps... []

SENATOR HARMS: You know, I don't think we should have to put a commission together to deal with this. []

HELEN MEEKS: Right. And perhaps it might be something as simple as, at the point in time when we do a survey in a facility and you send out the deficiency report, that goes to the facility administrator. By our state statute, that's where you send it because that's who is responsible and that's who you're dealing with. And perhaps something as simple as saying, in addition to the information going to that facility chief, then it ought to go to whoever owns that facility, which in this case is the state of Nebraska, whoever their governing authority is, if it's a private organization whoever their board of directors is. Perhaps that may be something that should be done because then there is an assurance that someone higher than the chief in the facility is aware of the issues that are going on or that have been cited. []

SENATOR HARMS: Yes, I think that the buck always stops at the top here, you know, whoever has to answer for this. You know, that's where it should go and the overall responsibility is where that should be discussed. Because, as I said as I view this, it's definitely in my mind that something really broke down that was seriously wrong with the system that we have today. So I don't...now what are your thoughts about that? []

HELEN MEEKS: Well, I'm not sure what I'm...what I'm being asked. []

SENATOR HARMS: I'm just...what I'm really asking is where did we break down. That's really... []

HELEN MEEKS: And I think I've answered that. I think, you know... []

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SENATOR HARMS: Okay. I feel comfortable with that, yeah. []

HELEN MEEKS: I think I've answered that... []

SENATOR HARMS: Thank you. []

HELEN MEEKS: ...to the best of my ability. []

SENATOR LATHROP: Senator Cornett. []

SENATOR CORNETT: I've read the paperwork. I just want a little bit more clarification. You go out and you do a survey. You find deficiencies. Who gets that deficiency report currently? I thought it was HHS, but you just said that it was the director of the facility. []

HELEN MEEKS: It goes to the director of the facility, gets the deficiency report. []

SENATOR CORNETT: Okay. So... []

HELEN MEEKS: And again, we leave it to... []

SENATOR CORNETT: And I understand you're not responsible for.. []

HELEN MEEKS: Yeah, right, for them to tell... []

SENATOR CORNETT: ...for Health and Human Services or for the facility, the running of the facility. []

HELEN MEEKS: Uh-huh. []

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SENATOR CORNETT: So the director is the only person that gets a copy of that report.
[]

HELEN MEEKS: Currently. []

SENATOR CORNETT: Currently. []

HELEN MEEKS: Uh-huh. []

SENATOR CORNETT: All right. What do you receive back again, a plan of action for correct... []

HELEN MEEKS: Plan of correction. []

SENATOR CORNETT: Plan of correction. []

HELEN MEEKS: Yes. []

SENATOR CORNETT: How many days is that from the time that they receive the... []

HELEN MEEKS: I think there is...I think it is ten days, they have ten working days to provide a plan of correction. []

SENATOR CORNETT: Who...do you happen to...and I know this is not your area. Do you happen to know who has to approve that plan of correction? []

HELEN MEEKS: We do. []

SENATOR CORNETT: Well, who draws up the plan of correction... []

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HELEN MEEKS: Oh, at the facility level. []

SENATOR CORNETT: ...at the facility? Is it the facility? Is it the supervisor above the facility in Health and Human Services? Do you know who does that? []

HELEN MEEKS: I don't know who does it as far as BSDC is concerned because there is no regulatory requirement in terms of the echelons within the organization of the facility. []

SENATOR CORNETT: So... []

HELEN MEEKS: We just expect it to come back to us with the chief, whoever is in charge of the facility. []

SENATOR CORNETT: So you wouldn't know if, for instance, the head of the facility even notified Health and Human Services about the deficiencies. []

HELEN MEEKS: No, we would not necessarily know that. []

SENATOR CORNETT: All right. So you receive the plan of correction within ten working days. []

HELEN MEEKS: Uh-huh. []

SENATOR CORNETT: Then do you have to approve that plan? []

HELEN MEEKS: Yes. []

SENATOR CORNETT: Okay. And who is responsible for approving the plan? []

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HELEN MEEKS: It's within the Licensure Unit. I have, for each facility type, facility or service type, there's an administrator under me and so that administrator reviews that plan in concert with the surveyors who were there on site and we look at it to see--and then sometimes I'm involved with that review--we look at it to see have they addressed the areas of the deficiency, that's one piece, and then whether or not we need to, depending on the nature of the deficiencies that were cited, do we need to actually go out back on site and take a look... []

SENATOR CORNETT: That was my next question. []

HELEN MEEKS: ...or is there something that... []

SENATOR CORNETT: If you're required by law to survey once a year... []

HELEN MEEKS: Uh-huh. []

SENATOR CORNETT: ...and you find significant deficiencies, you turn those over to the facility. They have ten days to develop a plan of correction. You look at the plan of correction. At what point do you go back out inside that year and resurvey? []

HELEN MEEKS: Okay. Thank you. We would go back out based on the date that they tell us they expect to have that deficiency corrected. []

SENATOR CORNETT: How many days are they given to correct that deficiency? []

HELEN MEEKS: It varies. Sometimes...we have a provision, we have the authority to do what we call a directed plan of correction and sometimes it can be...we will say you have to have this done within five days, depending on the nature of it. Let's say if they...we went into a facility and it was, you know, in the middle of summer and the air-conditioning wasn't working. We would say probably, when we did the deficiency

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statement, that would be one where we would direct them, you have to have your cooling system fixed by X date. []

SENATOR CORNETT: And then do you actually physically send someone back out to make sure the deficiencies have been corrected, or do you just take a written report, we corrected this? []

HELEN MEEKS: It could be either/or... []

SENATOR CORNETT: Depending on the level of deficiency? []

HELEN MEEKS: ...depending on the level of it. So we could specify a particular date. In many instances, we leave it to the facility to say when will they expect to be in compliance with this condition of participation, these standards underneath that condition, and then we base our revisit date on that date that the facility has provided. []

SENATOR CORNETT: Back to the line of questioning that Senator Harms has, where did the system break down, in the last couple of years it looks like it has snowballed until we are now facing losing federal funding for Beatrice. With the level of deficiencies that you were finding and the federal government was finding at Beatrice, how often has your office been going out and surveying and doing follow-ups on the deficiencies found? []

HELEN MEEKS: In the last year or... []

SENATOR CORNETT: Over the...we'll just say the last two or three years. []

HELEN MEEKS: Okay. At least...well, obviously, we were in there annually and then, you know, it depends on the number of complaints that came in. You know, we might have gotten 100. We have the numbers and we certainly can give you the numbers of

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complaints that came in from any facility type. []

SENATOR CORNETT: Well, I meant in regards to when you sent out the approval of the plan to correct the deficiencies, how many follow-ups did your office do? []

HELEN MEEKS: Okay. I think, and I would have to pull some notes, I think we've been in maybe on two or three follow-ups, probably more, and I will get my notes out and look at that. []

SENATOR CORNETT: You know what, you can provide that later. You don't have to go through the notes. []

HELEN MEEKS: Okay. Yeah, because we can tell you exactly the number of follow-ups that we have done at BSDC. []

SENATOR CORNETT: Okay. Could you provide that... []

HELEN MEEKS: Sure. []

SENATOR CORNETT: ...for the last four years in regards to the plan of actions and then what steps you took after you received those plans? []

HELEN MEEKS: Right. Because that information is in your... []

SENATOR CORNETT: Is it? []

HELEN MEEKS: It is in there. []

SENATOR CORNETT: Okay. []

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HELEN MEEKS: Because in there, in the three volume booklets, three volumes of notebooks that we've provided to Senator Lathrop, we listed here's the survey, then here are the follow-ups and the results of those follow-ups to every survey that has occurred at BSDC over the last ten years. []

SENATOR CORNETT: When you say...does it breakdown follow-ups in regards to actual on-site visits? []

HELEN MEEKS: Yeah, it will tell you that. Uh-huh. []

SENATOR CORNETT: Okay. Good. []

SENATOR LATHROP: Senator Adams. []

SENATOR ADAMS: Good morning. []

HELEN MEEKS: Good morning. []

SENATOR ADAMS: Thank you, Senator Lathrop. I noticed in the...one of the earlier sheets that was handed out, and again in your testimony, where beginning in 2006 CMS chose to do their own independent. Do you have any opinion as to why they said to the state, we're going to do our own independent surveys now? []

HELEN MEEKS: Yes. []

SENATOR ADAMS: Could you tell me what that is? []

HELEN MEEKS: CMS had indicated to our division, Division of Public Health, in the latter part of...let's see, I think it was '05, they presented us with some comparison data from facilities, ICF/MR facilities, across the nation how many surveys were conducted,

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how long you were in there, the number of deficiencies that were cited. And they indicated to us they were concerned about the number of deficiencies that we had cited at BSDC and, primarily, I think they were saying too fewer...too few. And CMS tends to take a real close look at state-operated facilities, large state-operated facilities. Many states have eliminated large ICF/MR facilities. Michigan, as an example, has one large one and that's it. Nebraska has BSDC. And CMS, frankly, looks at those that are state operated. And I think they had a concern about whether or not we were serving BSDC to the level of strong scrutiny, I guess, is my terminology, even though the times that they had been in there with us, and they had--they had gone on I think two monitoring visits to ICF/MRs in Nebraska between 2003 and 2006, prior to the time they went to BSDC in the latter part of 2006--they had come in and they watched us. When they do a monitoring visit they basically are watching us do the work that we are contracted with them to do. And they went us at BSDC and one of the facilities in Axtell. And we received no feedback from them indicating that they found deficient practices on our part. But they were concerned, we know that they were concerned, they made it known to us. And so we said, okay, well, you know, just because we don't cite deficiencies doesn't mean that we missed something. You can go in a hospital on any given day, you may find something. You can go in a nursing home on any given day, you may find something. You go back; you may not find anything. Look at the complaints that had come in from BSDC. Had we missed investigating any of those complaints? So we didn't get that real specific this is what you didn't do, but there was the general concern. They gave us comparative data. Dr. Schaefer and I met, we were in a meeting down in Kansas City. Then in April of 2007 a CMS official came to the department again expressing concerns, just general, you know, you just don't look like you're citing enough deficiencies at BSDC when we look at large facilities like this nationwide and you compare the number of deficiencies, that sort of thing. We took their concerns very seriously and we put together a plan to address their concerns, even though they did not ask us for one, and we laid out in that plan what we were going to do. We said we were going to monitor ourselves, we're going to send our surveyors--and we only had...at that time I think we had two vacant positions--we will send our surveyors back

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to your training, CMS, even though they had gone through that training before. We will, if you come in and do monitoring visits, if you come in and do what they call focused reviews with us, we would welcome the opportunity for you to do that. And so we submitted that plan in June of 2007 and that started toward implementing that plan. We were getting ready to do BSDC's survey in July, I believe. Actually, we actually did go in and do that survey. And before we were able to go back and do the revisit, CMS came in and did their own visit in the latter part of '06. []

SENATOR ADAMS: Thank you. []

SENATOR LATHROP: Do you have any other questions? []

SENATOR ADAMS: Not right now. []

SENATOR LATHROP: Okay. Senator Wallman. []

SENATOR WALLMAN: Thank you, Chairman Lathrop. Yeah, thanks for being here and thanks for you being in the people business. I know that's a tough business; thanks for doing it. And picking up on Senator Harms, the buck stops at the top, I mean President Truman. And it stops with us now. So we have to find a solution. And maybe we are being picked on, which we probably are. But in regard to this, you know, board of directors, elevators, banks, you know, we're seeing a different climate in this country of accountability and it bothers me. You think...how can we turn out future leaders for like the BSDCs and our governors, our presidents and our senators? I think our education system...can we hook into that somehow to breed dedication? You know, we're having trouble with workers. Do you have any ideas on that? []

HELEN MEEKS: Yes, certainly education helps. But I think people have to really care about what they do. And that doesn't mean it's all about education, in my view. Working with people with developmental disabilities, and certainly there are providers here I'm

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sure who can speak to this better than I can, you have to care about the people that you're working with. It's not about the...yes, you need to know the regulations. But it's about I have to treat these people with dignity and respect, and you use common sense approaches. I worked at BSDC and I went there in the seventies. And I considered it a blessing. But you have to have that dedication, that's my view. And that to me is part of the culture change and so forth. And again I'm not saying necessarily I don't believe that BSDC is the most terrible place in the world. There's been some bad outcomes, it can happen. But you have to be...you have to hold people accountable and you have to look at hiring and selecting people who really have a desire to help the people who are being served and who need to be cared for in that facility. That's my view. []

SENATOR WALLMAN: Thank you. []

SENATOR LATHROP: Senator Gay. []

SENATOR GAY: Thanks. Thank you. Helen, you had mentioned Michigan. This is a follow-up to Senator Adams question. But you are being proactive to go and say we're going to have our own solution, train our inspectors, which I commend you for doing. Then you kind of touched on this. So Michigan, nationwide does every state have these type of facilities, these large, large ICF/MRs? []

HELEN MEEKS: Some states, Senator, have eliminated their large... []

SENATOR GAY: How many? []

HELEN MEEKS: I don't know the number off the top of my head. We could probably get that. But most of the states, many of the states have gone to what is referred to as the ICF/MR smalls, which are the 15-beds type settings. I think because of the funding streams, you know, it's just probably easier to serve a smaller population. So several states have eliminated the large institutions. And the only reason I mention Michigan is

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just because I know that as we have been working with CMS here recently, they do what they call kind of a prep training prior to the time that Michigan surveyors goes into their large, that one large facility that is in...that's located in the state of Michigan, because you don't...it's kind of the proficiency issue. If you only inspect this type of facility only once your proficiency probably may not be theoretically as great if you were, you know, inspecting ten and so forth. And so CMS used Michigan as an example as they were working with us. And they said, yeah, we'll be...we'll come to you. And a lot of this we just do by teleconference as prep work, they said, because Michigan has only one large ICF/MR facility. Washington, D.C., as an example, I know that they've gone all small 15-beds or lower. And they had egregious problems in those a few years ago. And that started the national trend that CMS has been on there for several years in terms of looking at the survey agencies work a little bit more closely, because there were some egregious things that occurred in Washington, D.C. And so CMS set up these...this contract. And they had nationwide people going out in every state attending the surveys with the state surveyors. []

SENATOR GAY: Okay. So, I guess, the idea of what I'm getting at is if we're bucking a national trend to go to smaller facilities, then we're always probably never going to get out of the...from under a microscope. I know you're a national leader in these things, inspections and some of those. I don't know where we're at, but maybe that's something that we need to look into of, you know, what's the future, you know, because we're not looking...we're looking backwards. That's why we're all here. But I think Senator Harms and everyone else is saying, what are we doing to do proactively to be better again? Like you said, you worked there and it was (inaudible). And I think we need to go back there. So maybe we all need to focus on what's out in the future. Another thing, when you do, in that book probably it says this, but I don't have time to look at that right now. But training to me, staff training I'm talking about, whether it's Beatrice or a local community, is training a requirement? Can you talk about that a little bit of how do you train your staff, that they're doing best practices? And how do they stay informed of CMS changes that are coming? I mean, is there updates, bulletins? Can you talk about

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that a little bit. []

HELEN MEEKS: Yeah, there are staff training requirements. And the regulations may...it's broadly stated that you are to have a sufficient number of competent trained people. And the training is supposed to be commensurate with the services that you're going to be providing. So it's very broadly defined and it, in my view, should be because it gives the facility the flexibility to train their people in accordance with the needs of the residents that they are being cared for. There are some specific training. For instance for nurse aids there's a requirement that they've got to take a 40-hour course, that sort of thing. But that's a nurse aid whether you're going to be working in any type of setting, an ICF/MR or nursing facility, whatever. So the training requirements, it's broadly stated and it gives the facility the flexibility to train in accordance with their needs. So when we are in there surveying we look at if you have someone, for instance, who is on a ventilator, was their training for the direct care staff in taking care of that? And are they trained so that they know when they are supposed to call the nurse, because obviously the nurse isn't...they don't have a nurse on every living unit where there is a vent client. But the direct care staff needs to be trained in caring for that and then have the understanding--here are the signs and symptoms that you need to look for when you need to call the nurse, so that the nurse comes on board, does the nursing assessment, and then can decide this is time we need to call the physician, this person needs to be taken to the hospital. So we would be looking at it in terms of again, as Dr. Schaefer talked about earlier, patient needs, client needs. And the training needs to be commensurate with that. []

SENATOR GAY: Okay. And then would...so you said there are four inspectors that are out doing...is that the larger ICF/MRs, there's four inspectors? []

HELEN MEEKS: Yeah, right. []

SENATOR GAY: And you have staff of 157 to do all licensure. []

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HELEN MEEKS: Um-hum, right. []

SENATOR GAY: You got a lot, you got a big job, I know that. But the question is this, you are being proactive. You go to CMS and you say, show us what you want. How do you want us to inspect? So I commend you for doing that. The question is, they probably...do they get back to you or not. But is four enough? And should there be...are you looking into that? Saying, well gee, maybe we need some more, you know, if we're not doing it right. Have they ever got back to you? And are you looking...what steps are you taking to train future inspectors, because to me it sounds like it's not just something that anyone of us can just walk into and, oh by the way, I'm a quality inspector. What are you doing to train people in the future? I mean, we could add more staff or what's your plan? []

HELEN MEEKS: We are looking at, within the agency, whether or not we should be shifting resources. I think it would be pretty obvious to everybody to say four people cannot inspect to the degree that we need to. For ICF/MR facilities we have 155 CDDs, over 1,400 settings for home- and community-based waiver services. And so we are looking...Dr. Schaefer, Mr. Wyvill, at the resources that we have in the department. Should some of those resources perhaps be shifted from something else to, you know, regulatory oversight? I know that's one thing that is occurring within the agency. We've provided Dr. Schaefer some data in terms of, you know, complaints, the numbers and what you need to in order to make an informed decision about additional resources. Do you need to...and it may be a shifting. I'm not here saying, you know, it's going to be 10 new positions, 80 new positions. But I know that that's being looked at. []

SENATOR GAY: So it's being looked at. But, I guess, when is the answer going to be made or when would we know that we need 12? And I know people cringe at that, but I think Senator Wallman brought up a point and maybe we're seeing it in my industry, the financial services industry. You can have regulated us fine, but if they never show up, it

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doesn't do you much good. So there's a certain point here where...and I'm not a big regulatory person. But I think we owe it to the clients that we...and the parents, everyone that these people who are so vulnerable, that we're doing our job. We don't want to overdo it. But there's a happy medium and maybe we've slacked a little there. I don't know. I mean you're the expert on that. But I'm looking forward to saying here's how we're...and maybe you can't answer that. But maybe here's where we're going, I think it's important that we know that in the future. []

HELEN MEEKS: Yeah, yeah. And it isn't something that I have the answer to. []

SENATOR GAY: Yeah. []

SENATOR LATHROP: I want to ask a few questions. I was...we made a request and we've received, I think, 20,000 to 30,000 pages of material, something like that. So thank you for what you've provided. We have all kinds of people in the Capitol reading this stuff and trying to go through it. And I've had an opportunity to read some of it that's been kind of set aside. And as I was reviewing it maybe historically, and this is a question I was asking Dr. Schaefer. And that is originally, kind of historically your office was doing the inspections up to 2006. Is that true? []

HELEN MEEKS: That's correct. []

SENATOR LATHROP: And you did find some deficiencies. They were kind of, if there's such a thing as the every day kind of deficiencies, they were the sort of the every day, run-of-the-mill sort of deficiencies, general problems? []

HELEN MEEKS: Yeah, some of them were general problems. But, you know, some of...
[]

SENATOR LATHROP: You didn't identify instances of abuse and immediate jeopardy

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in, say, the five or six years before 2006? []

HELEN MEEKS: I'd have to look, Senator. But I know that we had cited deficiencies in the client protection area. And then was it to the extent or same degree that CMS's findings? I think that's where there might be some variance. I don't know off the top of my head if we had cited...I know that we had not cited BSDC as being out of compliance. Where I think CMS's survey they were out of compliance with, what, six of the eight conditions. And I don't believe that we had found them out of compliance with that many of the conditions on any of the surveys that we had done. []

SENATOR LATHROP: All right. You would have, as part of your job with the state and given your responsibilities, reviewed what CMS did in 2006 and 2007 and so far in 2008? That be true? []

HELEN MEEKS: Yes. []

SENATOR LATHROP: And as a general statement, they have found abuses and neglect and instances of neglect at Beatrice in the course of their inspections, is that true? []

HELEN MEEKS: They have. []

SENATOR LATHROP: And I was struck by a pleading that they filed in connection with the appeal done by the state of Nebraska where they summarized it, basically, in this fashion--they said, you have a personnel problem, staffing problems at Beatrice which leads you to move people around from cottage to cottage, from building to building, from assignment to assignment so that we have people that are unfamiliar coming in to a particular resident hall and filling in for people that have called in sick or maybe just for a person that we have not filled the position for. Would that be true? That's essentially their finding? []

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HELEN MEEKS: Yeah, I'm sure, yeah. []

SENATOR LATHROP: And the difficulty that that understaffing has presented is that you then have folks who don't know the client. So they really don't know when they have a behavioral issue or if that's sort of their baseline. You have folks that aren't trained to deal with a particular individual with whom they're being assigned. And the staffing problems are also causing a situation where they don't have opportunities to take the people who do work there and go get them the training they need. That would be a fair summary of what they found? []

HELEN MEEKS: Um-hum. Yeah, I think so. []

SENATOR LATHROP: And that has been a chronic condition. And really as I kind of went through this it looks like CMS has said, we've told you this is the problem, we've told you this is it, and by the way, all of this leads to unhappy people who are...they have a tough job to do, it's hard on job satisfaction when you're working too many hours, you don't have enough support. And now we're going to move them around to places that they're not familiar with, and all of a sudden we end up with abuses and neglects. And that's sort of the conclusion of CMS. []

HELEN MEEKS: I would agree with that assessment. []

SENATOR LATHROP: And then the state has come in, in response to what CMS has said in '06 and '07, and basically said, this is our plan to fix it. []

HELEN MEEKS: Well,... []

SENATOR LATHROP: They necessarily have to do that. []

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HELEN MEEKS: Are you talking...when you say the state, you're... []

SENATOR LATHROP: I'm not saying you, but... []

HELEN MEEKS: Oh, okay, thank you. Okay. []

SENATOR LATHROP: ...as you observe this, as someone who watches these inspections and this process, basically, the state has come in and said, this is our plan of correction. We're going to fix it in one manner or another. []

HELEN MEEKS: Yes. []

SENATOR LATHROP: Right? And they haven't gotten that done. That's really kind of what got them decertified. Would that be fair? []

HELEN MEEKS: Well, to some extent, because again when CMS did the visit at the end of '06 there was a revisit and there were still deficiencies found at the time of that revisit. They asked us to join them mid-2007 on another revisit, still deficiencies found. We have found, since we've started to do all of the complaints, we have found deficiencies that are...some of them involve neglect, abuse, those kinds of things. There's been, I think, one maybe two immediate jeopardy situations that we found as a result of a complaint visit. And so each time again the facility is given the opportunity to put in their plan of correction. And then, of course, CMS is going to be looking at that. And then we either jointly with them will go on sight and do a revisit or we may go by ourselves or they may go in and do a revisit. []

SENATOR LATHROP: Maybe the point I'm trying to make with these questions is this--is that we've been put together by the body, the Legislature put this commission together to investigate this. And it's really hard when we look at individual incidences of abuse and we say, well, that is abuse, and that is neglect. And we get so caught up in

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looking at incidences that we're groping around, as Senator Harms said we're groping around for what's the big picture problem. []

HELEN MEEKS: Um-hum. []

SENATOR LATHROP: And as I read the pleadings filed by Health and Human Services, CMS in this appeal they kind of summarized it sort of succinctly. You know, we don't have enough people and that leads to all sorts of problems. It leads to overtime, which leads to unhappy people who are tending to high needs patients. The hours that they're putting in because there aren't enough of them there is leading to a lack of training, we don't have time to train them and get them through the system. And that...if there's a big picture sort of an issue that's come out of the CMS reports that would be it, wouldn't it? []

HELEN MEEKS: I guess I wouldn't disagree with that. []

SENATOR LATHROP: Okay. This problem at Beatrice has led us to or led various people to talk about maybe the solution is to take...well, the Governor's five point plan that's been presented is to bring the population at Beatrice down to 200. I think I saw something this morning that said to reduce it down to 170 maybe by the end of next year. But the idea is to reduce the population. And that's only going to happen in one of two ways--one would be attrition, and the other would be moving them to a community-based program. That be true or can you think of another way? []

HELEN MEEKS: I would assume...yeah, I would assume so. []

SENATOR LATHROP: Okay. Okay. And that leads us to, all right, if we're moving them to the community, how do we know that there are going to be any safer there? Is the community look like a good idea? Helen, does the community-based programs look like a good idea today just because nobody is watching them the way they're watching

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Beatrice? []

HELEN MEEKS: I think from the regulatory oversight standpoint we've got to look at our regulations. And those are being looked at within the agency to see, because we had...the regulations had been worked on for a long time. And we've, as you know, gone through various reorganizations within the agency. And I know that Mr. Wyvill recently indicated we were going to reconvene to start working on those regulations. And I think that needs to happen. And I'm speaking again from the regulatory standpoint. You all have addressed that issue. How much...how many times do you get in there? What are the kinds of things that you look at when you go in there? And then again it's just not all about that piece but also what are the requirements that people who are going to be...who have a group home, what are they supposed to be doing and how are they going to be held accountable through the contracts, with the money that comes from the state, whether it's through Medicaid or some other source. So all of those pieces need to be in place, in my view from a regulatory standpoint and a day-to-day operation standpoint in order to ensure that, you know, community services...people in community who are served in programs that are community-based are being cared for properly. []

SENATOR LATHROP: Aside from the people that are already there and maybe whose families would like to see a little more oversight, you're suggesting though that before we make some kind of a wholesale move to community-based programs that we need to put something in place to make sure there are proper inspections and surveys. []

HELEN MEEKS: Yeah, yeah, I think our regulations really do need to be put in place and ready to go. []

SENATOR LATHROP: You mention that Mosaic operates ICF/MRs, three of them, in Axtell and Beatrice and also in Grand Island. Is that right? []

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HELEN MEEKS: Um-hum, yeah. I don't know if it's Mosaic or...I have the name, so I...yeah, Mosaic, yes. []

SENATOR LATHROP: That's on this list here. []

HELEN MEEKS: Right, yes, the three. []

SENATOR LATHROP: And are you involved in the surveys of those institutions? []

HELEN MEEKS: Yes. We survey them annually. []

SENATOR LATHROP: The one thing that we haven't done is look at those survey results. And I'm not sure...maybe I need to have you give me a little idea what they look like rather than to request and get another 10,000 pages. (Laugh) How are they comparing to Beatrice? Has CMS come in, Helen, and taken that and said, we're also going to look at Mosaic and how they're doing with the privatized ICF/MRs? []

HELEN MEEKS: CMS has not come in and conducted the annual certification survey for any of the Mosaic operations. They were in last week, I think, or week before now and did a monitoring visit with our surveyors and gave us glowing reports. We found some deficiencies. []

SENATOR LATHROP: They were glowing about your survey,... []

HELEN MEEKS: Yeah, about that we were following...yes. []

SENATOR LATHROP: ...your ability to do a survey or about Mosaic's... []

HELEN MEEKS: No, about our surveys, because they were there checking on us. []

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SENATOR LATHROP: Okay. []

HELEN MEEKS: And so that said, we were identifying...properly identifying deficiencies, if there were any. If we didn't find any we, you know,...so they gave us glowing marks. But we did have, we did find some deficiencies. I don't know the nature of the deficiencies that have been cited...that were cited on that survey or all the Mosaic surveys. That's something that we could do in a summary for you where you wouldn't get, you know, the 1,000 page job. We could give you a view if that's something that the committee... []

SENATOR LATHROP: That would be...I think it would be helpful for us. But can you put them side-by-side and tell us how Mosaic is doing. They're running the same kind of a facility the state runs at Beatrice, am I right? []

HELEN MEEKS: Yes. []

SENATOR LATHROP: They're... []

HELEN MEEKS: Under the same regulations. []

SENATOR LATHROP: Mosaic is running the ICF/MRs privately and Beatrice is running one as a state facility. How are they comparing to one another? []

HELEN MEEKS: Right. And we can put together a document that will give you that view. []

SENATOR LATHROP: You can't tell me today? []

HELEN MEEKS: I can't tell you today. []

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SENATOR LATHROP: Okay, I won't ask you to speculate. I think that's all I had. Senator Gay had a few questions and others. []

SENATOR GAY: Helen, this is follow-up to Senator Lathrop's about community-based settings. And I think some of us have questions. Right now I'm looking on page 2. You said there's 31 providers with that, and they have 1,460 different settings where clients are. The question is this, is somebody comes in and let's say more people were going to be served in a community-based setting. And right now we have 31. Is there...when you go out and they come in and say, I need a license, I want to enter this business, I want a license. Does the state have to give it to me if I meet all the requirements or do we cap those licenses? []

HELEN MEEKS: We do not have a cap on the number of licenses. []

SENATOR GAY: But you have to give the license to me if I meet all the requirements? []

HELEN MEEKS: If they meet, right, if they meet the requirements that are... []

SENATOR GAY: Okay, you have to do that. []

HELEN MEEKS: Yeah. []

SENATOR GAY: Okay. The second one is then if we do that, when you're looking at 31 different agencies, if we have to give them a license and they meet all the requirements, they get part of the waiver money. There's no priority system, there's no saying that, oh by the way, you top 10 do a much better job, and I don't know the...you top 10 do a much better job than the other 21, we're going to give you more money. We can't prioritize it that way? []

HELEN MEEKS: I don't know that, Senator. That's something...because we don't, public

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health doesn't administer the funding. []

SENATOR GAY: So that's... []

HELEN MEEKS: We look at them to see if they meet the requirements... []

SENATOR GAY: Okay. []

HELEN MEEKS: ...to be eligible... []

SENATOR GAY: I'll ask. I'll go find that out later. []

HELEN MEEKS: ...for funding. And the funding decision is made somewhere else. []

SENATOR GAY: Okay, I can find that out on my own. Thanks, Helen. []

SENATOR LATHROP: Senator Wallman. []

SENATOR WALLMAN: Thanks, Senator Lathrop. Yes, Helen, sorry about asking all these questions. But say I'm a private care provider and you write me up. Do I lose my license immediately or am I under jeopardy or do I have to... []

HELEN MEEKS: We have a range of penalties, Senator. And thank you for asking that question. There are a range of penalties that can be imposed on a healthcare facility or healthcare services license--everything from a fine, a monetary fine, which under state statute can be up to \$20,000. And we have fined facilities. And we can prohibit admissions. And we use that one a lot, because if we go out and find certain types of deficiencies that are going on, for instance they're not acquiring the medications that the physician has ordered for this person, that probably is going to lead us, when we inspect them if we find that, that would probably lead to a prohibition on admission,

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because we're seeing you aren't taking care of the people that you have there, so why would the state authorize you to expose this same kind of deficient practice with other people. So we can prohibit admissions until we see that they have corrected the problem. We can limit the types of admissions. We have found in some facilities where they may have a person who has real high medical needs and they have...there are...they have had some breakdowns in terms of care. We may limit them and say, you can continue to care for all of the other people. But you can no longer care for people who are on nasal gastric tubes, because you've not done that well. But we don't see that the place is bad enough that their license should be revoked or suspended. We can place the license on probation, meaning you can continue to operate but under certain terms and conditions. And we would lay those out in a notice to the facility--here are our findings, based upon this we're going to put your license on probation for...and we can put that license on probation for any period of time. And during that time we're going to be monitoring you to see if you're meeting those terms and conditions. We can suspend a license and for up to two years or we can revoke the license. If a license is revoked then the provider is prohibited from seeking to be relicensed until two years have transpired. So there are a range of penalties that can go on. Now, in every situation when the state says, here is what we are going to do to you, that provider has the opportunity for a hearing. They have to have due process. If you're looking at it under CMS's rules for certification, it's a somewhat similar process, not exactly the same as the state's. But like the Senator was summarizing, at this facility we found these problems, these problems, these problems, you have an opportunity to correct. Now, we've given you ten opportunities, you haven't corrected. CMS would likely say, now we're going to start imposing penalties. They can impose money to a civil penalty is what they call it. They can stop admissions. They can say we're not going to pay for any...they can't say we're...they say, we will not pay you for any new admissions until you fix this problem or you go on up the scale, so to speak, to the point where they say we are giving you notice that we are going to be terminating your provider agreement. So there's a range of penalties that are there. []

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SENATOR WALLMAN: And picking up on that, have our state facilities, no matter whether they may be private or public, ever...you get complaints from the League of Human Dignity, whether it be transportation or... []

HELEN MEEKS: Oh, no one, no one is prohibited from submitting complaints. And our complaints come from a variety of sources. []

SENATOR WALLMAN: Yeah, that's fine. Thanks. []

SENATOR LATHROP: Senator Cornett. []

SENATOR CORNETT: I wanted to go back to the community-based providers very quickly. You have four surveyors, correct,... []

HELEN MEEKS: That's correct. []

SENATOR CORNETT: ...for the state? []

HELEN MEEKS: Um-hum. []

SENATOR CORNETT: You are saying that there are 31 agencies. []

HELEN MEEKS: Um-hum. []

SENATOR CORNETT: And I'm going to exclude Mosaic, because they have the same inspection requirements as BSDC, correct? []

HELEN MEEKS: Right. []

SENATOR CORNETT: And under those 31 agencies you have 461 individual settings

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or patients. []

HELEN MEEKS: No, 1,400 and... []

SENATOR CORNETT: 1,400. []

HELEN MEEKS: Um-hum. []

SENATOR CORNETT: Okay. []

HELEN MEEKS: It's 1,460. []

SENATOR CORNETT: 1,460. []

HELEN MEEKS: Yeah. []

SENATOR CORNETT: And those are facilities that fall under the 15 person or they can be? []

HELEN MEEKS: No, these are the home- and community-based waiver providers. []

SENATOR CORNETT: Waiver providers, okay. When you have clients in those types of settings are all of those facilities in a four-year period inspected for...when...I got a little confused earlier when you said that you inspected by the regions, like Region 6, Region 5. Or do you just go through and randomly pick different facilities inside those regions for inspection during that four-year period or all facilities in that region inspected in a four-year period? []

HELEN MEEKS: Okay, let me clarify the four-year period. []

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SENATOR CORNETT: Okay. []

HELEN MEEKS: First of all, the home- and community-based waiver providers, they may not be, how can I put it? This is where it gets really mucky. If you're not caring for four people who have developmental disabilities,... []

SENATOR CORNETT: Right, if it's three people in an apartment, like you said, are... []

HELEN MEEKS: ...right, we don't have a licensing requirement in this state. So... []

SENATOR CORNETT: But more than four you have to have a license. []

HELEN MEEKS: Right. So some of these... []

SENATOR CORNETT: Okay, let's deal with the more than four. []

HELEN MEEKS: Yes. So some of these 1,460 don't fall under licensure, therefore we would not be randomly selecting up to 25 percent of them to survey. []

SENATOR CORNETT: How many people are...how many are...licenses are there in the state? []

HELEN MEEKS: How many...? []

SENATOR CORNETT: Licensed facilities are there in the state, excluding Mosaic. []

HELEN MEEKS: Of all types of healthcare facilities? []

SENATOR CORNETT: No, in developmental...the facilities we're talking about providing... []

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HELEN MEEKS: The one that care...there are 155 CDDs. []

SENATOR CORNETT: Okay. []

HELEN MEEKS: There are 4 ICF/MRs. []

SENATOR CORNETT: Right, which are the Mosaic's. []

HELEN MEEKS: Right... []

SENATOR CORNETT: Right. []

HELEN MEEKS: ...and BSDC. And then there are 31 providers that fall under the...that are funded through the waiver program. []

SENATOR CORNETT: That's the 31 number that came up...that I had mentioned earlier. Now when you say providers are you talking about individual group homes or are you talking about agencies that run those group homes? []

HELEN MEEKS: Agencies that run them, like Region 5 may be a provider. []

SENATOR CORNETT: Are those group homes? Out of those 31 providers, they are licensed. []

HELEN MEEKS: That they...they're...any setting that they are operating, any of these 31 providers, if they are operating a setting that has... []

SENATOR CORNETT: That is under four. []

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HELEN MEEKS: ...that has fewer than four there is no license in that setting. []

SENATOR CORNETT: Okay. With the ones that provide care for more than four, they have to have a license through the state. Are those people inspected? []

HELEN MEEKS: Yes. []

SENATOR CORNETT: How often are they inspected? []

HELEN MEEKS: Okay. Those would be centers or group homes for developmental disabled. Under our state statute we can inspect, we don't go in and inspect all of those annually. We can randomly select up to 25 percent of them to be surveyed on...inspected on an annual basis with no more than five years transpiring when they would be inspected. In addition, we can go in on complaints and we can go in for any other cause. And we list out in the regulation for cause, if there's some physical or natural disaster that happens or we get, you know, all of the staff is leaving, the administrator or whatever. There's a whole list of for cause things that we can go in and inspect a CDD for. []

SENATOR CORNETT: So are there group homes that provide care for more than five...four people that might not be inspected, might...I mean as a requirement? []

HELEN MEEKS: Ever? If...if ever...if they...ask me your question again. I'm trying to understand it. []

SENATOR CORNETT: Okay. If you're only inspecting 25 percent,... []

HELEN MEEKS: Um-hum. []

SENATOR CORNETT: ...and that's a random picking,... []

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HELEN MEEKS: Right. []

SENATOR CORNETT: ...are there...is it random by region of the state? Is it random by just going through and randomly picking them? How do you select what 25 percent are chosen? And are there people that are not chosen? I mean,... []

HELEN MEEKS: Every...every...in the category of CDDs, the 155, we randomly select 25 percent from the statewide. []

SENATOR CORNETT: Okay. []

HELEN MEEKS: And if, for instance, no one was lucky enough, no, no one was randomly selected, and we keep track of this, then we would go in and if no one had been selected over a five year period, we would inspect that facility. []

SENATOR CORNETT: Okay. []

HELEN MEEKS: So all of them... []

SENATOR CORNETT: And so they will get inspected. []

HELEN MEEKS: ...should be inspected within...once within five years at least once. []

SENATOR CORNETT: And is this done geographically or is it just random throughout the state? []

HELEN MEEKS: Across the state. []

SENATOR CORNETT: Okay, so your inspectors have to travel all over the state

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basically all the time,... []

HELEN MEEKS: Yes. []

SENATOR CORNETT: ...because you only have four inspectors for the whole state. []

HELEN MEEKS: Um-hum. []

SENATOR CORNETT: The federal government currently comes in and inspects Beatrice because it's a state run facility, correct? They can. []

HELEN MEEKS: They can, they can go into any ICF/MR facility. []

SENATOR CORNETT: Can...do they go into Mosaic and inspect? []

HELEN MEEKS: As I said earlier,... []

SENATOR CORNETT: I know you've done surveys. Have they done surveys? []

HELEN MEEKS: Independently, I don't think that they've gone into Mosaic and done an independent survey. They've been in there and done monitoring of us, but they haven't gone in, to the best of my knowledge, and done one. []

SENATOR CORNETT: And I assume that they do not go into any of the other agencies or homes that we're talking about. They leave that responsibility up to the state. []

HELEN MEEKS: CMS would not have anything to do with a CDD> []

SENATOR CORNETT: That's what I mean, they don't have any...correct. So... []

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HELEN MEEKS: They would not...CMS, the same branch... []

SENATOR CORNETT: They... []

HELEN MEEKS: ...the same branch of CMS would not necessarily. The same branch of CMS that looks...that has looked at BSDC, would not be looking at the home- and community-based waiver programs. []

SENATOR CORNETT: Who looks at the home- and community-based waiver programs? []

HELEN MEEKS: Again, they...the regulations are set up by the state under our Medicaid division. We serve as the survey agency for Medicaid for home- and community-based waiver programs. []

SENATOR CORNETT: So, basically, the last line of defense, if you want to call it, is your office for the home- and community-based. []

HELEN MEEKS: Tell me what you mean by "last line of defense?" []

SENATOR CORNETT: You are the people that go in and do the surveys and make those facilities accountable. []

HELEN MEEKS: We do this... []

SENATOR CORNETT: Is there anyone at that point that makes the state of Nebraska accountable for the people that are in home- and community-based care? []

HELEN MEEKS: We do the surveying and we turn the information over to DDS and Medicaid who makes the decision to stop funding them or whatever. []

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SENATOR CORNETT: Okay, that's what I was looking for. []

HELEN MEEKS: That's their decision, not ours. []

SENATOR CORNETT: Okay. Thank you. []

SENATOR LATHROP: I think that's it. []

HELEN MEEKS: Thank you. []

SENATOR LATHROP: I do want to say, just as an aside, I've run into a lot of people in state government in the last two years. And it is a pleasure to work with you. []

HELEN MEEKS: Thank you. []

SENATOR LATHROP: You have a command of the information, you present it well. And I have confidence that whatever you're in charge of is well run. So thank you for being here today. []

HELEN MEEKS: Thank you, Senator. []

SENATOR LATHROP: I think we're going to take a little bit of a break, all right? Before we do that though, can I get a show of hands of folks that are interested in testifying. I'm trying to look behind you to see, where we at, about five? Four or five? Do you want to work through lunch or take a lunch and come back at one? I think, why don't we just take a 15 minute break and then we'll come back. And if it's just four or five people, we'll finish up. []

BREAK []

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ROGER STORTENBECKER: (Exhibit 4) Members of the committee, thanks for the opportunity today. My name is Roger Stortenbecker, R-o-g-e-r S-t-o-r-t-e-n-b-e-c-k-e-r. I serve as the chief operating officer for Developmental Services of Nebraska. We're one of the community-based DD providers that we've been talking about earlier today. We provide services in Lincoln, Omaha and Kearney to approximately 162 people. August marked my 31st anniversary of being in the business of supporting people with developmental disabilities in Nebraska, 14 of those years I worked for Health and Human Services in the developmental disability system, about 4 of those years I was the director of the DD system. The current Title 205 that regulates community-based DD services in their current form, I was the last guy to sit there at the word processor into the wee hours of the morning writing those rules and regs and working with the Legislature in trying to make sense of them all. So I'm fairly familiar with what the rules and regulations are. The testimony that I've handed out to you was what I was planning on in the order I was planning on. But for sake of continuity, if it's okay with the committee, what I would like to do is step back into a couple of comments that were made a little bit of the discussion earlier. I think it would be important to clarify that what regulation and licensure licenses are CDDs--Centers for the Developmentally Disabled. They are health facilities and they are licensed as such. But there is no location where people live who have services funded by the state of Nebraska through the developmental disability system where there isn't some state oversight. In addition to regulation and licensure, there is the division of developmental disabilities that has a staff of at least six program specialists. And their job is to serve as the liaison to organizations like mine and all the other organizations in the state. They conduct certification reviews. Granted, they're not licensing, but they are certification, and all locations are subject to their certification review. All services are subject to their certification review. So while regulation and licensure certifies a health facility, the division of developmental disabilities certifies the services that are provided there, if that makes sense. In addition to the DD system central office, there are literally hundreds of service coordinators who...at least one service coordinator sits on the IPP team, the

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interdisciplinary team that develops the program plan for every person in services. And that service coordinator has a responsibility, and I'm here to tell you they carry it out, to monitor those services every day for every person on their caseload. They do that in every home, in every vocational setting. And they have the authority to charge us with a plan of correction through their service monitoring form and format. So it isn't exactly true that there are some places that don't...well, it is true there are some places that don't get licensed. But it is also true that every place has a certification review activity in it. So that seemed important for me to bring that out. Another comment that was made in response to a question, well rather than comment on the comment, I'll reply to the question that was asked. Generally the question was, if there is a community-based provider that is sub-performing, are there any financial sanctions, are there any fines or sanctions of any kind? When I was at the department we designed what I think is a pretty good system. The service authorizations are individualized. Every person who receives a service has an authorization that is unique to them based upon their need level. That authorization does not belong to service providers, it belongs to the individual. So if an individual or their team member or their advocate or their service coordinator, if anybody feels like they're not getting proper service that person can take the money and run. They can vote with their feet. They can go to any other qualified certified provider in the state. The money will follow them. So there is a control there, a tension there that if I don't do a good job at DSN I'm going to lose business and pretty soon I'll be closed. And I can tell you for a fact it happens. We have people leave us because they don't like something we've done or something that we won't do. We have people come to us because some other provider didn't do something that they wanted done or a wide number of reasons. It is a very dynamic service population for us, especially in the Lincoln and Omaha areas where there is a plethora of service opportunities, service provider opportunities. So we see a lot of movement. So there are some controls, some tensions in place to help with that service quality idea. With regard to regulations, monitoring and oversight community-based services we've had a lot of discussion here this morning about do we need to, and I'm certainly paraphrasing here, but my perception of what's been going on is do we...how do we prevent bad things

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from happening in the future? Do we need to throw more regulations on it, more supervision, more oversight? I guess I would suggest that what we probably need is different rules and regulations and oversight. The people that we're supporting in community-based programs, the mix of their needs is considerably different today than it has been 30 years ago when this system was designed. Even with its updates--the subsequent writing of new rules and regulations--the population continues to change and their needs change. I think probably from my perspective the better question will be, how can we attract and retain high quality frontline workers in the community long enough that they can learn all the rules and regulations and all of our technologies and they can gain experience. We don't really have a recruitment problem. It's actually fairly easy for DSN to recruit people to come and do the work that we do, but it's incredibly difficult to keep them. Sometimes it's a money issue. Our starting salary is right around that \$20,000 a year mark. Well, there's not a lot of people can make a go at \$20,000. So what we'll find is a lot of our staff have several jobs. And when the job gets tough where we are, those other part-time jobs may pay less, but they look a little easier and maybe it's time to move on, I don't need the headache. So really, I think, Senator Lathrop, you were hitting on it earlier when you were asking about BSDC and do we have kind of an issue of train away as you will. But if a lot of the people are always new, really, how far are you getting? We're spending a lot of time in the classroom. We do that at DSN. We've got a required 40 hours of training for every staff person that comes through the door. We've got another three months of close supervision on-the-job training by our managers. We have a manager in training program where we're trying to grow our next generation of managers. And we can get our staff through that initial training, the 40 hours required, but we found ourselves, for economic reasons, having to take a look at what is essential, what has to be in place for this employee to be successful, because what we know is there's a good chance that in three months as many as 50 percent of those people we hired are going to be gone. So we have to start taking a look at what is essential versus what really develops the skill. Within three months it's hard for the people that we employ to develop necessary relationships that they support. If you can imagine that some of the things that we ask our staff to do can include everything from

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helping someone go to their church, helping someone do personal hygiene items, helping someone get to their family, to their doctor's appointments, things like that. They're pretty...they're fairly personal kinds of things. In a high staff turnover situation it's very hard to get that relationship built between the people that we're here to support and the people that are there to support them. And I can tell you no matter where I've worked in these 31 years, without that relationship it just doesn't get done. So I think where we need to go, a lot of our solution, both at Beatrice and in community-based programs is we're going to have to dial in on the quality of our frontline workforce. We employ almost 500 people in Nebraska. And that's a lot of training, that's a lot of oversight. There's a lot of rules and regulations. And if folks are only going to be here three to six months it's going to be incredibly difficult to give them the experience and the skills they need first to even understand what those regulations means and then, second, to live by them and develop a good skill, a good talent for this work. Well, the attachment that I've given you, pages 2 and 3 here, I kind of late in my planning decided that what I should do is give you just some insight into some of the major oversight and monitoring and controls that are in place already in community-based programs. Now, as I went through this exercise the thing that kept coming back to my mind is if this is not enough rules and regulations and oversight already, then what the heck. What can it be? I'm not sure that throwing more on top of this is really going to improve our outcomes. So I think we haven't quite gotten to the root cause of the systemic problems that we do have. And, I guess, to reiterate my perspective is it's right down there in how are we recruiting, how are we hiring, what are we able to pay, what are the benefits, what are the challenges at that frontline staff level. Once we can get somebody up to a middle management and higher job we've got people for life. They'll hang in there. Well, look at me, 31 years later I'm still here. But I got out of direct support a long time ago, back at Lancaster Office of Mental Retardation. And back then the starting salary was \$13,000 a year. So we're not a lot further ahead, even inflation adjusted, so...with regard to really one of the...one of my primary interests here is how do we help those people who are ready, willing and able to move from Beatrice to community-based services. I think we're going to have to take a hard look. I get to see every one of those

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referrals that comes out, and so do our three area directors. And we talk about every single one of them. In every case we do talk about the service authorization that's coming with that person. Money is important. If we can't pay our way, we're not going to be in business. And we have a responsibility to people who are currently in our services that we maintain financial health so that they still have a place to get their services. But just as important we look at what are the need levels of the people who are waiting for a placement out in the community. It's a mix of need levels. It could be anything from nursing level of care, it could be significant behavioral supports, psychological support, therapy support and those kinds of things. All those things that are included in that daily rate that Beatrice gets to provide their services are there and available for that person. Now as they move into the community we take a look at what do we have available for us. One of the reasons community-based services are quite a bit less expensive than ICF/MR services is not all the services are there in community-based. We don't have nurses on staff. Our reimbursement rate doesn't include nurses. In fact our reimbursement rates prohibit us from using that money to pay for nursing services, it has to be for habilitation. We pay for the places where people live with room and board payments, largely one of the reasons why we congregate people. Our philosophy is congregating is not necessarily a good thing, but take a look at the rent, utilities and the cost of living and the SSI payments of around \$700 a month, you have to congregate people in order to find a place for them to live. That's a straight pass through. We don't keep anything off the top of that. In fact most of the months last year we found ourselves subsidizing the room and board for the people that we support. But that's a thing we do. That helps us on our mission, that gets us down the road. So one of the things I think we have to do is take a look at when folks are moving from BSDC person by person, individual by individual, what is their support need? Where are they going to go and how are we going to get that need met? Now, the way things are right now we don't set the rate, we don't set the intervention units and we can't negotiate it. It's here is the person, here's what we're willing to pay, take it or leave it. Well, a lot of times we say, I got to leave it. And as time goes on that seems to be what a lot of other providers are starting to say. DSN used to go out on a limb, say, oh, I think we can do this

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because in several months we might be able to get those behaviors under control. That's risky business these days because there's a lot of pressure. It might be nine out of ten days we're pretty successful with a person. But when they decompensate, when they have something, maybe a mental health need that brings them into the attention of the local police, the neighborhood or even HHSS now all of a sudden we're doing plans of correction and it's not so economical anymore. So there's a lot of challenges there. I don't want to say that it's impossible to overcome. But I think it's a thing that we're really going to have to dig down into and say, why is it a provider would decide in community-based services that they won't support someone. And it is bigger than money. Money is a chunk of it because you have to pay the bills. But it is bigger than money. We don't want to take somebody, for example, to Kearney if they're going to need a service that's only available in Omaha. If our opening is in Kearney and we have to go to Omaha a couple times a week, we can't afford to do it. That's a big trip and there's not that amount of transportation built into the reimbursement rate. We can't afford to open a place in Omaha if we don't have a current opening that's appropriate for the person. Again we're back to the room and board issue--one place for one person, just can't afford to do that. It's not right to tell people they have to move in three at a time. They might not make good roommates. They might not like living in Omaha, all three of them. So there's a lot of things to juggle there. So it's...yes, it's complicated, but I think it's pretty straightforward. It always goes back to the same thing--what does that person need, can you do it and are we putting forth the resources as a statewide system in order to make that happen. I think one of the other things that's kind of important about the changing system several years ago when I was at the department the eligibility criteria was that you had to have a primary diagnosis of a developmental disability. Along the lines about the same time when there was a consent decree to move people from the regional center into community-based programs if they didn't need the acute regional center care our eligibility changed in DD services. Rather than having a primary diagnosis of developmental disability, developmental disabilities needed to be present. So what could happen then literally is a person whose primary need was a mental health need could find themselves eligible for DD services. In

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addition to that then we've had a prioritization system that the only entitlement in Nebraska right now is you have entitlement to service coordination if you're eligible. And if you're a transition student from a Nebraska high school you have entitlement to replace your lost school, essentially a day service. But there's no entitlement to residential. The way that you get into residential services for the last several years was you had to be in a crisis; it's a prioritization process that was laid out in the Developmental Disabilities Service Act. What that means though is that the people who have been coming into residential services for quite some time have been people in crisis. When the reimbursement rates were developed, clear back in the Deloitte Touche days, that rate was built upon several platform ideas. The first one in residential services it was a one to four ratio. So it enjoyed the economies of a one to many supervision span. In vocational services it was one to ten. It was also based upon a mix of high, moderate and low need people. Now, at that time we used a tool that would render this person has high need, this person has moderate need, this person has low need. Now when you do a thing like that in a funding type situation it's easy to see how there would be need level creep. You know, if there's more money for people who are high need, then gradually everybody starts to look like they're higher need because that's where the money is. Well, we took away that high, moderate, low need and just did some averages into the reimbursement rate. But what's happening now is that in fact, because of the prioritization system, our mix is changing to higher need. And a lot of those folks are becoming high need because of significant behavioral causes that they can't stay where they are currently, whether that's with a family or just on the street. So our mix is changing. Now another group that we've become aware of, DSN had a grant with Nebraska Vocational Rehab to look into the prevalence rate of persons with acquired brain injuries in the DD services system. We were one grant recipient, Goodwill, Greater Nebraska and Grand Island also received a grant. And they were doing the same kind of a thing in the outpatient mental health field. What we found out is that there is a significant number of people that we're providing services to that are eligible and that come through the DD system who have acquired brain injuries. And as we worked through that grant, it was three years, we just finished it. As we worked

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through that grant one of the things that we wanted to find out was does the community-based DD system work well for persons with acquired brain injury. Certainly, you can be eligible and the funding mechanisms and all of that are there. But really does it work well? Does it meet needs? What we found out is that, yeah, the structure probably does work. So in terms of there's a staff and there's a state agency and funding can come from the Legislature through the department and all those kinds of things. But what we did discover is that there are some differences in the technologies that we should be using. Regulations don't really prohibit us from using those new technologies. In fact, I would hold that the regulations almost support what we discovered, which is the more you use punitive contingencies after a bad behavior of someone we support the chances are good that if you punish them what they'll remember is that you're a punisher. Well, earlier we talked about relationship is important. Well, so what kind of a relationship do we have? It's a bad one. Plus, with many of the people that we supported with acquired brain injuries remembering that contingency the next time the stimulus presented itself wasn't there anyway. So we tried to apply that then to all the services noncontingent...or nonpunishing contingencies. So I think there is some updating in the rules and regulations. Now, I think there is also some updating in how we determine how much funding should be available to a person who has brain injuries, how much funding should be available and how we distribute it, how we monitor it or dole it out to people who have dual diagnosis. I think our system, our service system is getting a little more complex, not quite stratified yet, but it's a little more complex. And so we keep applying this DD model to this ever-changing service population. So if we can dig into that and if we can improve that I'm encouraged to hear that there is going to be another look at rules and regulations. The last time it took about ten years to try and get a graph set of regs out. And they still weren't what was going to work. So I'm glad we're not giving up on it; it still needs work. If we can get these things solved in the community-based program, I think it's kind of gives us some clues as to what we're going to have to do to meet the needs of people who want to be from Beatrice into the community. That's essentially what I've prepared. And I've got a whole lot of wind here (laugh), so I better shut up. []

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SENATOR LATHROP: It sounds like you have a unique perspective as a witness. So I'm sure it's going to invite some questions. []

ROGER STORTENBECKER: Good, that's...I hope so. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Roger, since you've been with the system for, what, 31 years you said? []

ROGER STORTENBECKER: Yes. []

SENATOR STUTHMAN: Thirty-one years, with the population at Beatrice how many of those people that are receiving services do you feel would be eligible or could go to a community-based provider? Ten percent, half? []

ROGER STORTENBECKER: I wish I could answer that way, I can't. What I would say is as many people as we could find the appropriate services in the community, if they want to move out they could move out. Now, what percent is that? I suppose it's not beyond belief that it could be 100 percent. But to do that we'd have to take a look at what are those needs, because there are some significant needs of people who live there. We'd have to take a look at those needs and we would have to adequately support them in community-based programs. To do anything less would be shameful and it would be a recipe for failure. I hope that answers your question. []

SENATOR STUTHMAN: Yes. And also, when you...your last sentence there, you know, I feel there isn't adequate services in a community-based setting at the present time to truly, you know, take care of those individuals. Would you say that would be...? []

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ROGER STORTENBECKER: I would agree with that, absolutely. In some of the rural areas across the state, and I...my hat is off to the folks who are operating services in very rural areas. If I had someone...if I was providing services in Valentine to someone who needed acute psychiatric help and I'd have to drive them down to North Platte or Kearney or someplace like that, I don't know how I'd do it, because you never know when the need is going to present itself. And we're out there working with \$9-an-hour frontline staff, working in a one to many ratio, there's a whole lot of decisions have to be made instantly. Okay, do we call somebody in? It's the middle of the night, I'm the only person here working, there's two other people. This person is having an acute psychiatric moment here. I need to do something. How do I do that? There's a whole lot of things has to be built into place before we could make that kind of a placement. []

SENATOR STUTHMAN: What is your interpretation of community as far as an individual? Does that mean that he moves back closer to his original community or does that mean that he just moves to a community that provides service, and it could be 200 miles further from what it is today at Beatrice that's where he could be moved to. []

ROGER STORTENBECKER: I think historically we've talked about community primarily as an alternative to institutional care, so a community being an alternative to Beatrice State Developmental Center, for example. With regard to your question, what is community to an individual, it might be moving back home. When I was at the department we had a lot of discussions about that, what equals community, in fact what equals a Nebraskan if somebody from another state found themselves here in Nebraska receiving services at the Beatrice State Developmental Center and now they say they want to move home. Okay, is home in Nebraska or is it in whatever their state of origin was. As we researched it the legal stuff about it was, well, it's where they intend to be and reside and stay. So community, community could be for that individual, if they say, well, I have these, figuratively speaking, I have these kinds of needs and those needs can be met in Omaha. They move there, that's their community. If they decide later, ah, I want to live in Grand Island. They move there, that's their community. So when we

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think about people moving to the community it does involve a lot of choice on the part of the individual, but that choice has to be made within the context of what services are available. Some made the choice they wanted to live in Randolph, they're going to have to talk to Alan Zavodny about, hey, I know you don't have a program there but can you do this for me. And he'll have to make a decision. That may or may not be their community in the end. []

SENATOR STUTHMAN: Is there any consideration to family members as far as, you know, where they relocate these people? I mean, I always think family support for individuals that are in this situation is very, very important. And if you move them further away and they will be seeing them fewer times throughout the year could be more of a stress on the individual than before. []

ROGER STORTENBECKER: Generally, that is true. There are some isolated cases where family contact has been counterproductive. Those are usually things that we try and work through, spend a lot of time. In fact, as DSN, which is kind of atypical, we also provide community-based mental health services both short-term and patient residential and outpatient. In those kinds of situations we'll have our licensed mental health practitioners get into that team meeting, that program planning team meeting and try to work through those differences if they exist between the family and the person. You know, all that is a thing we can offer if the family and the person what to do that. Generally though, if a person doesn't have a guardian and they're age of majority their opinion weighs very heavily. And if they say, I want to live in mom and dad's hometown, okay, we'll go that direction. They say, no, I want to be in Scottsbluff because they're in Omaha, we'll try and move that direction. []

SENATOR STUTHMAN: Okay, thank you. []

ROGER STORTENBECKER: You bet. []

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SENATOR LATHROP: Senator Cornett. []

SENATOR CORNETT: Over the course of the hearings that we've had I've asked the question a number of times and gotten different answers. And yours again, for Senator Stuthman, was a little bit different, sir. If Beatrice was going to be closed tomorrow, and I'm not talking that that is my intent at all, I'm just saying if, I've heard that the community-based services will expand to meet the need, the money is there if the money follows the patient. Community-based services will expand based on the need. You don't think that we're there now. We don't have enough community-based services to place the people, to deal with the higher needs, maybe behavioral people that are residents at Beatrice. Am I correct? []

ROGER STORTENBECKER: That's correct. If your time line is literally tomorrow, if the doors close tomorrow, we had to find someplace else for all those people to live it would be an enormous struggle. The people that DSN employs are not nursing staff. We are not going to know how to do those G-tubes, we're not going to know how to do nebulizers, we're not going to know how to do any of those more invasive nursing-type services. []

SENATOR CORNETT: Let me move away from the nursing services a little bit. When you said that you could see eventually that 100 percent of the people at Beatrice, theoretically, could be moved to community-based services do you see available services for the high need behaviorally disordered? There are a lot of people at Beatrice that they have two on one care currently, two staff members sit with them. Is that type of service available in community-based at this time? []

ROGER STORTENBECKER: In some cases yes. []

SENATOR CORNETT: And where are those services located, all in the eastern part of the state, is it spread out through the state? How far would be moving people from their

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families? []

ROGER STORTENBECKER: You know, I really don't know how many outstate providers are doing that. DSN is serving two people right now who have in excess of one to one funding. It might not be two to one. []

SENATOR CORNETT: Two to one, but it's in excess of one to one. []

ROGER STORTENBECKER: It's in excess of one to one. And in those cases the reason for that funding is because of a certain level of the risk that person presents either to themselves or to others. It could be that they have what would be recognized, not adjudicated, recognized as sexually aggressive behaviors. []

SENATOR CORNETT: That's...oh, go ahead. []

ROGER STORTENBECKER: And so in order to provide, as best as we can as a state, assurances that something bad doesn't come out of that in a community-based setting what we do is we staff-up. My suggestion earlier for maybe we need to take a look at our technologies is staffing-up is a stopgap. It's not necessarily real treatment. And so to be successful, to move folks of significantly high behavioral needs into the community, I think, we're going to have to take a look at what does it really take for them. Does it exist in the community? And if it doesn't, where are we going to put it, because we're going to have the economy of scale kind of an issue where the best of the best experts in their field of dealing with significantly aggressive behaviors, those are expensive folks. And you can't have one in Omaha, one in Lincoln, one in York, one in Kearney, one in Grand Island, you can't do it. []

SENATOR CORNETT: That was exactly where I was headed, because you do have a population that is aggressive, behaviorally aggressive, do you feel that it is appropriate, that the community-based settings currently are safe enough both for that person and

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for the community around them? []

ROGER STORTENBECKER: That would depend on the person. You know, I've been surprised over the years. People that I've read their background on it's looked risky, and the staff have convinced me we can do this. I've had to hide my eyes and cross my fingers. And they've done it, they've found the way to do it. So I'm really hesitant to say that there are somebody who absolutely cannot or somebody who absolutely will. It just really depends on a whole lot of factors that have to come together. []

SENATOR CORNETT: Who would be determining the factors? []

ROGER STORTENBECKER: Probably a combination of the interdisciplinary team that would include the clinicians from BSDC, it would include provider staff, it would include Health and Human Services from their oversight perspective and the service coordinator. It would be an interdisciplinary team including those folks who have treated the person. []

SENATOR CORNETT: My biggest fear is both for the safety of the individual, but then the safety, if we move them into community-based, the people surrounding them if the right decisions aren't made in regard to placement. I mean, I understand what you're saying about economy of scale. It may be the best...I mean, maybe the best alternative is keeping the people that are that behaviorally disordered where they can receive treatment for all their behaviors at one time and when you said, you know, you can't necessarily have the funding for one in Lincoln and one in Omaha. []

ROGER STORTENBECKER: Mostly my response there is one of geographical separation, huge geographical separation. If, on the other hand...and where would people go to live, what would be their community. If, on the other hand, there was a, you know at the risk of using a cliché here, if there was a center for excellence in Lincoln, people could move to Lincoln and we could have the economy of scale it would take to

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have a person in Lincoln to oversee the support needs of that person or several people who had moved from Beatrice. []

SENATOR CORNETT: Okay, thank you very much. []

ROGER STORTENBECKER: Sure. []

SENATOR LATHROP: Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. Yeah, thanks for being here, Roger. I want to reemphasize I'm not against community-based care. And I think we ought to be working together. You know, if I...just say I'm a community, you know, I'm a provider and I take a sexual predator and that person rapes my neighbor's girl, 14- or 15-year-old girl. Am I at risk or is that individual at risk? Am I liable? []

ROGER STORTENBECKER: Well, the way it seems to work today? []

SENATOR WALLMAN: Yeah. []

ROGER STORTENBECKER: Yes. []

SENATOR WALLMAN: So... []

ROGER STORTENBECKER: The people find me really quickly in those situations. They... []

SENATOR WALLMAN: So I think we need both, but thank you. []

ROGER STORTENBECKER: Yeah, yeah. []

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SENATOR LATHROP: I do have a few questions for you. It sounded like the first point you were making with us is...it was right on the heels of talking to Helen Meeks where we asked about the number of inspectors. You're saying there are other safeguards in place for a person in the community and they are the service coordinator, which each person has, and they can make a complaint to...they can pick up the phone and call the police, they could talk to Adult Protective Services. There's some people that could make a complaint to and then there is the Division of Developmental Disability Services. They have a certain number of people who are involved in or interface with the people who are getting the care, allowing another opportunity for them to complain or express concerns about the care. []

ROGER STORTENBECKER: Yes. []

SENATOR LATHROP: And then, of course, the other safeguard is that, if you don't like the guy who's driving you from where you live to the doctor's office, you can choose a different provider and, as you say, vote with your feet. []

ROGER STORTENBECKER: Yes. []

SENATOR LATHROP: That was the first point that you tried to make or that you did make. You talked about the turnover rate for community-based program or your program. What's your turnover rate? In a year's time how many people do you employ, if I can ask, how many people do you employ and how many of them are going to turnover in a year's time? []

ROGER STORTENBECKER: We employ around 450. Every day it's a little bit different. We rely a lot of college age students because we do support a number of people who have aggressive behaviors, old guys like me are just going to get hurt if we're working in that environment. So we need people who are healthy, fit and able to work with some of those folks. Our turnover rate two years ago was about 80 percent. []

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SENATOR LATHROP: Was what? []

ROGER STORTENBECKER: Eighty percent. []

SENATOR LATHROP: Eight-oh? []

ROGER STORTENBECKER: Eight-oh, um-hum. []

SENATOR LATHROP: And is that of all 400 people? []

ROGER STORTENBECKER: Yes. []

SENATOR LATHROP: So two years ago you had to replace 80 percent of the 400 people. []

ROGER STORTENBECKER: Yeah, yeah, yeah. The way that we talk to our area directors and their coordinators that are really tenants was that we're going to have to step-up our onsite supervision and modeling, and we're going to have to do it on nights and weekends and overnights because what we have, literally, are locations that chances are best that if an employee has a question, eight out of ten times they're going to ask somebody who's just as green as they are, what should I do. Now, last year we improved that by quite a bit. We are probably, although I haven't seen the numbers yet, we are probably closer to a 50 percent turnover. []

SENATOR LATHROP: Are...community-based programs typically have a higher turnover rate than Beatrice? []

ROGER STORTENBECKER: I don't know the answer to that. I don't know what Beatrice's turnover is. []

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SENATOR LATHROP: You said that you use college students, fit people to do this work because it can be physical and in some cases involve a confrontation. []

ROGER STORTENBECKER: Um-hum, yes. []

SENATOR LATHROP: So are you recruiting people that have it as...it seems to me that when I look at the folks that are working at Beatrice and stick around they are people who find it a rewarding experience to work with the developmentally disabled. Are you looking for a different crowd when you're trying to staff community-based programs? []

ROGER STORTENBECKER: No, no. We're looking for the same kinds of things that BSDC would be looking for. If we were to hire someone who is fit and able to work in a confrontational setting, if they were confrontational themselves or that's what they were about, that would be horrible. []

SENATOR LATHROP: Yeah, they are gone. []

ROGER STORTENBECKER: Yeah, well they don't get through the door. Out of...out of those several hundred people that we hire in our recruitment strategies, currently, about half the people who apply actually get an interview. Out of the people who actually get an interview only about half of those get a job. And of the ones who get a job, some smaller number, I apologize I don't know off the top of my head, some smaller number actually get all the way through our training. []

SENATOR LATHROP: Well, at 50 percent, that's a very high turnover rate. []

ROGER STORTENBECKER: Yeah, it is. []

SENATOR LATHROP: And I've seen some numbers, that's higher than Beatrice... []

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ROGER STORTENBECKER: Yeah. []

SENATOR LATHROP: ...Development Center. What do you attribute the turnover rate to, your 50 percent turnover rate, because it really affects the continuity of care doesn't it? []

ROGER STORTENBECKER: Yes it does, yes it does. Well, I think, it probably has something to do with what we're paying, where we are and the availability of competition for other jobs. When we're out there starting people off on average about \$9 an hour, there's a lot of jobs out there that pay \$9 an hour. Unfortunately when the economy's bad and other business closes, that's when we get a lot of applications. But you know when Verizon moves into town, they've got some glitzy glossy billboards, come work for us, with some great looking people on it and we pay you great and there's good benefits. That's pretty attractive to a lot of people that we employ. So I think it has a lot to do with the challenges of the work, with the hours--we're 24 hours a day, 365 days a year. It has a lot to do with the wages. We do offer a pretty good benefits program, but people who are 25 and younger don't really care about our IRA, that kind of...health insurance. A lot of them are still on mom and dad's plan if they're at the universities. They really don't care about that. So it really comes down to how much cash in their pocket and it's difficult for us to compete. I don't know what Beatrice pays, but I heard that it was considerably more than that. So that... []

SENATOR LATHROP: It's all relative, isn't it? []

ROGER STORTENBECKER: Yeah, yeah. []

SENATOR LATHROP: Considerably more may be \$1.50 (laughter). []

ROGER STORTENBECKER: Yeah, that's right. []

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SENATOR LATHROP: Okay. Well, I appreciate your coming down here today. Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. Yeah, another question, please. How many of these direct care providers are providing for a child of their own or a sibling or a brother and sister, you know? []

ROGER STORTENBECKER: Oh, my goodness. []

SENATOR WALLMAN: Do you have an idea? []

ROGER STORTENBECKER: No, I really don't, several. []

SENATOR WALLMAN: They would probably stay on board. That would probably be... []

ROGER STORTENBECKER: In fact we even tried to target that group for our recruitment. What we thought was if we could find families, two-income families with kids, what we could offer is while one of the parents is working during the day, one parent could stay home and watch the child and that other parent could come work for us on a night or a weekend and the other parent could watch. It really didn't seem good to me, but my kids are older and I don't have to worry about that anymore. But it just really didn't stick, it didn't work as well. But there are a number of people who have their own kids, they work for us, and they work other jobs. []

SENATOR WALLMAN: Okay. Thanks. []

ROGER STORTENBECKER: Yeah. []

SENATOR LATHROP: Senator Cornett. []

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SENATOR CORNETT: I guess the thing that concerns me the most is this committee is meeting on Beatrice and part of the problem at Beatrice is the staffing problems. And if you have even a 50 percent turnover, the heart of the matter is that's worse than Beatrice in the way of staffing turnover. What are your other staffing issues? How is your overtime? How many people do you have on suspension at any given time because of complaints? I believe at the last hearing they had--what was it--almost a third of the employees at any given time on suspension for investigation of complaints. How do you compare? How do you handle complaints? How many people percentagewise do you have suspended? How much overtime do you run annually or monthly? And what are your provisions if people call in? I mean... []

ROGER STORTENBECKER: Yeah. See if I can knock those out in the order that you asked them. Fifty percent turnover rate is DSN's approximate experience. It might not be the experience of Region I, II, III, IV, V or any of the other providers. []

SENATOR CORNETT: Okay. I understand that. []

ROGER STORTENBECKER: Okay. If there's an allegation of abuse/neglect, we are required, just as every community-based provider is, to complete an internal investigation. We put the employee who is accused of abuse/neglect on suspension immediately pending the outcome of that investigation. []

SENATOR CORNETT: Suspension with pay or without pay? []

ROGER STORTENBECKER: Well, it is suspension without pay and that the employee is cleared, than if they would have worked a shift in that time that we were conducting the investigation, we'll pay them for those hours that they lost. Due to the nature of the shift work, what we try to do when we do an investigation is we'll put the person on suspension, we'll try and get them interviewed and wrap it up before their next shift

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would come around. Doesn't always work like that. If we determine, we don't even wait for Protection and Safety to make their determination because we report all of our investigations to Protection and Safety, and then that goes on to the DD system and Regulation, Licensure, if we determine that employee didn't act according to our policy and procedure or if we determine that it was abusive or neglectful, we separate them immediately. All those come past me. I see all those investigations. I'm the guy that watches for the system's issue: Is this a second or third one I've seen from a location? Has it come from a certain area program? Is it coming from a certain residential manager or a vocational or a coordinator? With regard to vacancy, I've been at BSN for six years and I think I'm accurate in saying there's probably not been a single month where we've claimed every intervention unit that was available to be delivered. Now, I don't know that that's unusual. When we built the system several years ago, we knew that there would be vacancy days where somebody was out of services or they might not have wanted to participate or there might have been some other circumstance that would have prevented all of the units from getting delivered. So we wrote the rules and regulations that you can claim up to the authorized or the actual, whichever's less. So I don't think it's unusual to say we don't claim all the intervention units. With regard to overtime, we have excessive overtime. There are certain times when we just have to bite the bullet. There might not be intervention units that there to pay for a staff person who's supporting a person who's having a significant behavioral episode. But in order for us to be successful, for that person to be successful, we still have to staff it. So every month we run intervention reports, and it bounces around what percent of our total payroll goes to overtime. Our policy is zero overtime unless the area director approves it personally. I can tell you every payroll there's considerable overtime. []

SENATOR CORNETT: Is that overtime because patients needs significant intervention as you just said, or is it because of a staffing shortage? []

ROGER STORTENBECKER: It's both. []

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SENATOR CORNETT: Both. Have you ever considered yourself fully staffed? []

ROGER STORTENBECKER: No. []

SENATOR CORNETT: Okay. Thank you. []

SENATOR LATHROP: I think that's it. []

ROGER STORTENBECKER: Okay. Thank you very much. []

SENATOR LATHROP: Thank you very much for coming down here and for your testimony and your insight. []

ROGER STORTENBECKER: Thank you. []

ALAN ZAVODNY: (Exhibit 5) Senator Lathrop, members of the committee, let me be the first to bid you good afternoon. My name is Alan Zavodny, A-l-a-n Z-a-v-o-d-n-y, and I'm the chief executive officer of NorthStar Services, and I'm also testifying as the president of the Nebraska Association of Service Providers. NorthStar provides supports to people in 22 counties in northeastern Nebraska. We have roughly 540 employees and support 330 people. We have area programs in Bloomfield, Columbus, Norfolk, Oakland, O'Neill, South Sioux City, Wayne, we get the Valentine issues, and Fremont. In the prepared testimony that's been handed to you, I talked a little bit about the background of developmental disabilities services. I won't go over that. You can read that at your leisure. I would like to follow up on a few things that have come up in previous testimony. Our turnover rate runs roughly 36 percent. In some of our communities, like Bloomfield and O'Neill, it's sometimes as low as 12 percent or 9 percent. Again, I think Senator Lathrop was on the right track, it's relative. In Bloomfield, we're one of the best employers going; Norfolk, not so much. So those things do factor into how successful you are in those areas. And to address overtime, we have a

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significant amount in Norfolk, other areas not so much. Some of the reasons for that might be if someone's in the hospital, a lot of times we will eat the cost and have a staff with them just for the familiarity of someone, a familiar face there at their bedside when you have tubes and people coming in and doing things. Something we're not able to be funded for, but we think is the right thing to do. And then, you know, we have staff that go on maternity leave, those kinds of things, so overtime does occur. What I have experienced and I've listened to the testimonies over the several hearings that you have held, not to take away from anyone who's testified whatsoever, but it's been a little frustrating because I hear what the issues are. Let me tell you what all the problems are, but it's been a little short on solutions. I'm going to get myself in a lot of trouble today because I'm going to give you solutions and that's not going to make everybody happy, but someone's going to have to step up here already and say, here's what we're going to do. Okay. So if they start throwing things at me, just ignore that. It could happen. The first is funding methodology. That's a formula that was designed by Deloitte Touche, as you've heard, then it was Touche Ross. That was early in the 1990's. And I think I should probably state here, I've been doing this for 27 years. June 15, 1981, I was really skinny and I had hair (laugh). So obviously I've changed a little since then. Don't be giggling over there, Senator Stuthman. I know what you're thinking. But that document, the methodology was a formula designed to assign cost for doing business, if you will. It had the staffing component which was based on 90 percent of a Tech I at Beatrice. And as you've heard, Beatrice can't even really hire the Tech I except for some substitutes because the pay is too low on what we're asking people to do is very difficult work for that kind of pay. You will also probably note, and this was according to Sandy Sostad's testimony which I thought was very helpful, that methodology needs currently about 95.5 percent of that 90 percent or it would take about \$3.5 million to fund you at that Tech I rate. So even funding that wouldn't get you to probably a really good competitive raise. And we are also fighting the issues of increased costs in a lot of areas, worker's comp, insurance, property and liability, natural gas keeps going up, electricity, all those things, fuel obviously. You've all had to fill your cars to get here today. So the current reality is the reimbursement rates really don't

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have much of a margin for the cost of our doing business. My recommendations would be it is way overdue to study the costs of providing services in the community. It's crucial that an effort be made to revisit the situation soon. I would suggest a zero-based approach, it costs what it costs. And then we can make the decisions we need to make of how much we're willing to commit to have these services provided. While increases have been appreciated, we have to deal with the reality that developmental disability services have not been a priority. When the state has enjoyed large reserves, we've been told that we need to give money back to the taxpayer, which I certainly understand. When times are more difficult, the message is we can't afford it this year. What you learn from that is it's never a good time. The ultimate political challenge we get is soon to follow: Tell us who we should cut so you can get your money. I would respectfully suggest that the premise of that premise of that question is flawed. So we need a funding system that's based on the Tech II position at BSDC and we need a formula that recognizes increases in operating expenses which are the costs of doing business. Issue number two is the objective assessment process or the ICAP tool you've heard some about. In theory that's an idea that's long overdue and it's needed. And what that essentially does is it assures that a person with similar needs in Omaha gets the same level of services as the same person in Scottsbluff. But understand that it is proportionate based on available resources, it's not truly based on what the person needs; it's based on their allocation of the pie that's there. Whether it's not enough to fill you up is a totally different question. Recommendation on that would be we need a system based on staff intensity needed for people. We would be much better served to evaluate the amount of staff intervention a person needs and base it on a ratio for 24-hour, at least, assisted services. Issue number three, BSDC. It's been my personal observation...I've been there a few times and I was area director in Fairbury, Nebraska, for around five years from 1991 to 1996, so I got to Beatrice quite a bit more often. And I would say in my recent visits, the morale is low. I had people asking me for jobs until they were found out we were pretty far away and certainly they lived in that area. And the reasons are probably more complicated than I can address, but I can tell you some of the things that I heard was what the CMS investigations, Department of Justice

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investigations, and running about 100 open shifts, it's a pretty tough place to work, and the overtime has been well documented. I know I have an opinion that puts me at odds with some people, but I think BSDC is necessary but it's not sustainable at its current size. Beatrice is a community of about 12,000 people. We provide supports to about 100 more people spread out over 22 counties, and we provide services in all the communities I mentioned earlier and it's difficult for us to recruit enough staff to do everything we need to do. As a matter of fact, we've been contracting because residential services really haven't had a formula that brings people into those since Governor Nelson's blueprint in 1996. Services were made...people were entitled to day services and so what we have done is slowly...if it's not being paid for, you see it shrink, and that's what we're seeing in our residential. So we are going the opposite direction of what you're looking for as far as capacity, and I think that should be something that would probably be concerning to you as you look at these issues. My recommendation would be to expend the ITS program at Beatrice. It's a valuable resource. There are people there who are used to working with some high intense behaviors. One of the problems we run into is if you have someone in the community and you have an emergency protective custody issue, we are a lot of times having a very difficult time finding anywhere to go with that person, and local law enforcement is wanting transport. They figure if it's a person with developmental disability, that's you as an agency's responsibility to do. So what we do is we get a driver and a person on each side of someone in a backseat of a little Ford Taurus and we hope that Norfolk can take us or maybe there's another opening at Omaha or somewhere and we make some long trips. It's not a good situation. Sometimes we've had the only opening in the whole state's in Scottsbluff. That's not a really good way to do this. The other thing that I think is a monumental problem is we talked about what are the limitations of community-based. I think safety that Senator Cornett mentioned is a really big thing. You want to never get off the front page is let someone burn down a city block in Bloomfield, Nebraska. You'll never get your reputation back. And a lot of times the referrals we're getting are people who have issues of setting fires. There may be sexual offenders, and we are really careful in making sure we don't make promises we can't keep. The worst thing we could

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do is try to say we think we can do something, then have a bad outcome because you never overcome that. You also have some people with violent behavior that chew up your staff, meaning you get a reputation, nobody's going to want to come work for you or the staff keeps saying, I'm going somewhere else for a buck less because I'm not going to get my glasses broken and bruises and that kind of thing. That's a reality in what we do. And so I hate to be as blunt about that, but I think you need to realize that's part of what you're up against too. The other thing that I think Beatrice absolutely needs to do is probably get a panel of I would recommend maybe nine. I don't know what the number is, but of people to evaluate every single person there, from 1 to 275, if that's still the number they're at, and say this person is best served in Beatrice. The number one person who is best served here is number one. And you go down to 275 really could be in the community very easily and it's able to do. The problem is do we have the political will to do that because now you're not really giving people the choice of Beatrice. You're going to have to say, look, Olmstead says you have the opportunity to have the least restrictive, but it doesn't guarantee you a placement necessarily exactly where you want to if you don't make Beatrice an option. That's the problem you're running unless you prioritized in some manner, you will never get Beatrice low enough to what you need to do. The referrals we're getting, and I don't want you to misunderstand, I don't want someone to come around later and say community-based isn't our answer because they're saying no to everyone. We're saying no to the people that we don't believe we can provide supports to. There are many people at Beatrice who could do extremely well in the community. The other thing that's happening is we're getting people with needs and the service units that are assigned to them don't seem to match that need level, so you've got to be really careful. In assisted settings, you're required for 24 hours a day, 365 days a year. If you accept someone, no matter what those units are, the expectation is 24-hour of continual care and supervision. If someone has very little units and high need, it's very difficult to make that work in many ways. BSDC must change its culture and must reinvent itself. And that's easy for me to sit here and say, doing it would be a lot harder, but there are ways that that could be done. The waiver, I think this is something that I would really like to see our state look

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at. My recommendation for that is we're due for a rewrite. I'd really like to see us focus on outcomes rather than the habilitation because what the habilitation does, and you do what you're paid for, so that's what you're going to go out and spend the most time focusing on. The problem is we're measuring what we're doing with people every minute of the day which doesn't have much impact on what their outcome in life is. Someone many years ago much smarter than I told me if you want to see what somebody's quality of life is, see how they spend their money. Are they going bowling? Are they doing leisure things? Do they take trips? Do they spend...where do they spend the money? Follow the money and you'll see what kind of life a person has. It's something where we're so concerned as providers of being sure we can account for what a person's doing every minute that we're losing sight of the bigger picture and I think that's problematic. What is paid for becomes the most important thing. Contracts, they become cumbersome. They have been used in the past to circumvent regulations and policies because they are a path of least resistance. This should not be used to replace the process to impose rules. And I would recommend that we have actual contract negotiations as opposed to the department saying here's your contract, take it or leave it, you're agreeing to all these things whether you want to or not. Services coordination, those are the people that are in our programs every day. Now, Helen testified of what reg and licensure does, but I want you to understand that through the DDD division, there are state employees who are there every day monitoring, looking what going on, and following people throughout their journey in our services. I would like to see...and I understand there are issues with the state union and needing to right performance standards, but I would recommend a choice in services coordination. You could have a state system, but I have a problem with the funder also being one of the people who monitor. There's an inherent conflict of interest. I would like to see services coordination be a choice people can make. We talk about choice all the time, maybe they would like someone other than the state of Nebraska being that person who coordinates their services. Finally, regulations, we have a lot of them. Roger provided to you what they are. But we need to simplify them. To give you a brief history on regulations, they've tried to work on them several times. I think we ran into some turf battles to be quite honest

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sometimes. And when we started this about 1998, several people have had name changes since then because it's taken so long, people have been married, not married, those kinds of things. People who have started this process have gone through a lot of changes and we're still sitting with no movement on the regs. It's taken us 30-plus years to get to this point. It's unrealistic to believe the solutions are simple and can be done quickly. We must start, however, because we have totally lost our way. The answer is not to throw money at the problem, but I think some reallocation might certainly help. We must establish capacity. We need to learn from the LB1083, which was when we were talking about people coming out of the regional centers and we didn't build a community capacity. We need to be smarter and not let history repeat itself by making the same mistake. Without community-based being ready, we are shifting a problem from Beatrice to the communities, and that would be shame on us if we allowed that to happen. We are down...I'd just like to say, the system is not stable as it currently is, and that's obvious from the reports. You've heard from Nebraska Advocacy Services, the Auditor of Public Accounts, CMS, Department of Justice, and others demonstrate the major flaws in the system. I will tell you that I don't think we'll have residential services to speak of within ten years in this state if we don't do something quickly because all of the providers are continuing to contract because people are coming into the residential services. And it gets hard, we have a lot of aging parents, the baby boomers, the people who have lived at home their whole lives because parents felt that obligation to take care of them. They're going to be coming into the system and where are they going to go if they don't have a place to live and we're contracting? We are providing, NorthStar, 37,000 fewer units in the last year than we did the year before. That's roughly \$740,000 reduction in our revenue. And I would just close by saying I think it's incumbent to bundle all this to work together to find what the solutions are, but we need to get going.

[]

SENATOR LATHROP: Thanks. It's good to have somebody come in and start the dialogue on the solutions because I think that's going to be our next focus. But Senator Cornett. []

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SENATOR CORNETT: Alan, why...we keep hearing testimony that community-based...there's a trend moving toward community-based services. If that is the case, why are the community-based programs contracting? Why do you have \$3 quarters of a million less than you did last year? []

ALAN ZAVODNY: That's a really good question. []

SENATOR CORNETT: Where is the money going? Where are the people going? []

ALAN ZAVODNY: Well, and there are multiply answers to that. People are moving, they get older, they might need to go to nursing homes. That happens. We have people that have been in...after the Horacek decision in the early seventies, people came to us in their 30s, a lot of those people are passing on, sometimes there are medical issue. So those things are happening, but the bigger issue of why residential is contracting is the only way to get residential services right now is to be what's called a "priority one," which means you're in imminent danger of being homeless or physical danger. And there aren't very many of those, at least coming to us in the rural parts of the state because parents are taking care of people at home and stuff, and the state is only funding students transitioning out of the schools for day services. We can go help them find jobs. We can work on interview skills, those kinds of things. But they're not funding people to come move into those CDD capacities that Helen talked about. Those capacities are great, but I don't think we could even hire enough people if we totally went to capacities. []

SENATOR CORNETT: So I just want to make sure I'm clear on this, it is a component on it that is basically attrition, they're moving to nursing homes, they're passing away. But people are still being born since the seventies when this...with developmental disabilities. Are we not providing the services that we once did and we're not expecting the family members more and more to keep their children at home for longer and longer

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period, which brings us to the question of the waiting list. []

ALAN ZAVODNY: That's exactly it. That is exactly it. The reason you have the waiting list you do is if a person is living at home with their parents and they're safe, they have food and they have shelter, we're not providing those services. []

SENATOR CORNETT: And they only come into immediate danger when those parents are no longer physically able to care for them. []

ALAN ZAVODNY: Mom dies and dad's ready to go to the nursing home. []

SENATOR CORNETT: So regardless of the quality of life that the parents have then and/or the child had, we're not providing services. []

ALAN ZAVODNY: We are not. []

SENATOR CORNETT: Thank you. []

SENATOR LATHROP: That's it. []

ALAN ZAVODNY: Thanks. []

SENATOR LATHROP: Thank you very much for your testimony. Can I see a show of hands? I ran us through the lunch hour. I thought we were going to have four people. Are we...okay. Three more. It's close. []

TAMMY WESTFALL: (Exhibit 6) Senator Lathrop and members of the committee, my name is Tammy Westfall, W-e-s-t-f-a-l-l, and I am the regional vice president of Mosaic Services here in Nebraska. I appreciate the opportunity to provide testimony today, and we hope that this testimony will help guide the state's future in providing appropriate

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services to all citizens with developmental disabilities. I am here today to provide an overview of our services. And today what I plan on doing is not talking about community-based services that we provide because that's already been done and we're part of the trade association, but to talk about our three ICF facilities. Mosaic was formed on July 1, 2003, by the consolidation of Nebraska-born Lutheran ministries. Bethphage began in 1913 in Axtell, Nebraska, and Martin Lutheran Homes began in 1925 in Sterling, Nebraska. Our national headquarters is located in Omaha, Nebraska, and we currently provide services to over 800 people here in Nebraska across 12 communities, and to over 3,000 individuals across the United States. Mosaic operates the only three private ICF/MRs in Nebraska: the Beatrice campus, Bethphage village in Axtell, and our nine-bed facility in Grand Island. These three facilities serve 245 people. Almost 98 percent of our funding is based...comes from Medicaid. The funding methodology has been based upon prior year facility cost reports which contain caps on certain costs, plus an add-on inflation factor. In recent years, there has been no methodology for establishing the add-on inflation factor. The appropriations for these services have not been adequate to cover the inflationary costs such as utilities, food, fuel, personal care supplies, several of the things that Alan mentioned earlier, not to mention wage increases. Without a significant increase in funding, Mosaic is unable to increase our starting wages for direct support staff. Due to the limited funding increases, Mosaic's starting wages have not increased for over six years. And remember, I'm talking strictly about our ICFs right now. The average starting wage is \$8.15, \$8.15 an hour. These low wages and the current economy have led to increases in staff shortages. The staffing shortages are placing a greater burden on our current staff to cover our open positions. The services for 245 people with severe disabilities are in jeopardy unless the issue is addressed. Mosaic's ICFs are regulated and monitored by Centers for Medicaid and Medicare and also the state of Nebraska, and I won't go into that in any more detail because Helen mentioned all of that earlier today. We also hold a two-year network certification by the Council on Quality and Leadership. The council focuses on quality through the use of basic assurances and personal outcome measures. Within the past two years, we have seen changes in the interpretations of

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the regulations. The interpretation and enforcement have created greater expectations and a drain on our limited resources. We will continue to support the state's plan in transitioning people from BSDC into our community and ICF settings, and we will work with the state to develop a system of care and supports for people with developmental disabilities. In order to meet the needs of our current population and support the transition to community-based services, the funding methodology should ensure adequate appropriations to allow pay adjustment for staff that is competitive to the market and to cover the recent inflationary costs. Estimated increase in appropriation requested is \$6 million. The state's portion is approximately \$2.4 million. This would allow us to bring our starting wages up to \$11 and hour, and to cover the recent inflationary costs. We recognize that \$2.4 million is a lot of money to request, but we feel it is an investment the state needs to make to maintain to provide quality services for the 245 people that we are committed to providing services and supports to in our ICFs. We would like to thank you for the opportunity and time to consider our testimony today. Mosaic is committed to partnering with the state to improve services for all Nebraska citizens, and we would like to encourage you to visit our facilities so that you have a better understanding of the services that we provide. And we would also be happy to provide you with any further information that you may need. []

SENATOR LATHROP: Very good. []

TAMMY WESTFALL: Thank you. []

SENATOR LATHROP: Thank you. Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. Thank you for coming here. I enjoyed your comments and investment and we consider cost all the time. I think it is an investment in our people in what we would be doing. Thank you. []

SENATOR LATHROP: I think...oh, Senator Gay. []

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SENATOR GAY: Quick question maybe. When you talked about the funding and Medicaid, earlier we talked about Medicaid as a, you know, you ask for the money and you get a portion and that's always our problem. But is there a private pay that you also get on your budget strictly based on Medicaid or do you get private pay? Do you get donations? Do you get...how... []

TAMMY WESTFALL: Three percent. We get a variety of money comes in for most if it. We only have one private pay in all of our three ICFs, so the rest of that could be from donations from the community. []

SENATOR GAY: So it's all...so 99 percent of your funding is Medicaid funding only? []

TAMMY WESTFALL: Um-hum. []

SENATOR GAY: Okay. That's what I wondered. Thank you. []

TAMMY WESTFALL: Um-hum. []

SENATOR LATHROP: Senator Adams. []

SENATOR ADAMS: Do you think that even at \$11 an hour, given labor shortage across the state, that you're going to have the people that you need? []

TAMMY WESTFALL: You know, right now to be honest with you, Senator Adams, we're...I'm going to use Axtell as an example. We too right now are using temporary staff to backfill the positions that we have open right now. So even if we were at \$11 an hour, because when you look at our Axtell community and we've got what we've got a community-based setting out in Holdrege, there's staff shortages. They're just...because of what the economy and the gas prices and stuff...because you know we're pulling our

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population of employees from surrounding communities and they can't afford, when you get the younger kids and they're driving to and from a great distance, they can't afford even gas in their vehicles to get to work. []

SENATOR ADAMS: But what about in rural Nebraska your ability to find psychologists, psychiatrists, that kind of help? []

TAMMY WESTFALL: That's a huge struggle. Even in our community-based settings we struggle. We cannot get, you know, the medical or behavioral health support out into those areas, and what Alan was talking about earlier is when you do have somebody is in a crisis, you do. You load them up, you transport them yourself, and hope that there's a hospital that will take them to get them through their crisis. And unfortunately it's strictly a quick fix because it's getting them through a real quick crisis and then they come back and you've got to be able to deal with that. So yeah, the behavioral health supports and the mental health supports are very limited when you get out into rural Nebraska. []

SENATOR ADAMS: So if you have a client with severe behavioral problem at any moment in time, you would handle that similar than to law enforcement in the area that was called into a situation. You have to find a place for them. []

TAMMY WESTFALL: Right because as Alan mentioned, the police will not do any transporting for us and so we either...now, we have obviously, we end up, you know, you hope for the best like I said that you can get somebody into a hospital setting. But anymore that's harder and harder to find because it's limited. There's only so many slots even in the hospital for mental health crisis. []

SENATOR ADAMS: Are we finding--if you don't mind--are you finding that are there any of these critical access hospitals in rural areas that are designating bed space for this kind of thing or is it just not in the financials to make it happen? []

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TAMMY WESTFALL: No, they don't designate for our population in particular, but for mental...just strictly there's so many mental health beds. But there's not that many, and there's only so many of the hospitals that even serve youth. I mean that's even limited in and of itself, you know, because we ran into a crisis out in our Axtell campus in December of 2007 and we had a huge time in getting that individual the services that they needed. And what it did is we ended up...all of the providers ended up clashing with one another because everybody would say it was all ended up being about money because there was not the financial resources, you know, to provide this person the supports that they needed. And fortunately we were able to get the individual into the IDIS program at BSDC for a 30-day eval. []

SENATOR ADAMS: Okay. []

SENATOR LATHROP: Senator Gay. []

SENATOR GAY: Do you have the TeleHealth in Axtell? []

TAMMY WESTFALL: We're looking at that in Axtell right now to do that. []

SENATOR GAY: I was in Kearney last week and they have that with a psychiatrist on duty 24/7 at Richard Young. I mean, it's a different scenario, but they deal with youth and adults and that population. And I was under the impression it's not being used as much as it could be, so I think that might be something you should look into a little. They flat out said it's not being used probably as much as we could utilize these tools we have, technology. So it might be a solution to look at in the future. []

TAMMY WESTFALL: And we did, Senator Gay, here, oh it's probably been maybe now close to six months ago, we have been working with a lot of Region III providers out in that area with service coordination, the hospitals, both Richard Young, Mary Laning you know to try to come up with some solutions. And that's one thing that we did discuss

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and that's why Mosaic Axtell is currently going to look at that. Yeah. []

SENATOR GAY: Okay. []

SENATOR LATHROP: Very good. Thank you for your testimony. []

TAMMY WESTFALL: Thank you. []

SENATOR LATHROP: I think we're down to one more person. []

MONICA BREITINGER: You know, I'm not a provider, I'm a parent. Okay. []

SENATOR LATHROP: We'll hear from you. []

MONICA BREITINGER: I'll be less than ten minutes. I didn't come to testify today, but what I hear is frightening to me as a parent of a child at BSDC because he may be on that frontline to get discharged. Just tell you a little bit about him and tell you what I know. He's 35. He's been there 12 years. []

SENATOR LATHROP: Ma'am, why don't we have you tell us your name first so we know who's talking to us today. []

MONICA BREITINGER: Oh, okay. Monica Breitinge, B-r-e-i-t-i-n-g-e-r. He's lived there 12 years. He lived in community one year. When he went to BSDC, he was on five psychotropic medicines. Those were in the glory years. They took him off everything. They said you can't learn rules, you can't follow directions if you're on all those meds. When he went to community, then his behavior was not so good and the first thing they wanted to do was to put him back on meds again. And you know that's just an uphill more meds, more meds, more meds. That's not really living. I could see that the care was deteriorating at BSDC, and you know we parents went to the administration there

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and here and the message we got we were told try and get along. So we saw things through that weren't right. Yes, we came here and they said try and get along. At one time I was ARC review person in Omaha, and this has been a while back. But some of the things that I saw is that if you have a small group home and there's two people there supervising, they become friends. And what I saw in that situation only one person would come to work and they would cover for the other person. Other person never came to work, nobody ever knew that there weren't two people there. So we did point it out to Encore and I think they took steps to correct it. But that's what happens in those small group homes, those people become good friends and they cover for each other. So they're not likely to report anything that goes on in those homes because that person is their friend. Also one day we went on a picnic with a staff. You know, we have vehicles at BSDC. You can't use your private vehicles, but they do in the community. The vehicle that one of the staff members used to transport clients was so old it didn't have seat belts. So these kinds of things are scary to a person that knows what goes on or used to go on in a community. I know what's different about BSDC and the community. It's the long-term employees. That is the key. It's the DT IIIs who can anticipate a problem. They worked there long enough they can anticipate a problem and they can smooth it over. They know what to do. Even some of the long-term employees aren't very good, but somehow BSDC has picked out key people. And on my son's unit, when things were getting bad...you know I live in BSDC. I'm there five out of seven days a week. I go in the morning, sometimes in the afternoon, sometimes at night. I'm around there a lot. And so even though sometimes I go and I wouldn't know any of the staff people on his unit, and I think this is not good. But in my mind I think the next staff, there's going to be somebody who knows what's going on, and maybe when things are going right they can correct it. But in the community with people who are not experienced in shift after shift, I think they're just asking for trouble. And I want to know how the state arrived at 170 people. I don't know if they pull numbers out of the air or if there's some reason or some scientific that that's what they're going to reduce to. I don't know. I've never heard how they arrive at numbers. Mystery. Somebody mentioned suspensions. Well, I told you, you know, when you have three people in a house and

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the people that are working there are friends, there's probably not going to be a whole lot or suspensions because they're not going to report on each other. And you mention the police coming in someplace. Well, at BSDC what I've witnessed is sometimes a client is way out of control, running or whatever, and there probably will be...and then after a while it's like maybe four staff just kind of gather around this person, talk him down, quiet him down, and there's no...they don't call the police. Of course they don't have to because they have the staff, but I see them just quietly talk, talk, talk, talk, but still ready to intervene in case something else happens. You mention, Senator Cornett, less people. You know, 90 percent of Down's syndrome children are aborted now. So there are less. []

SENATOR CORNETT: Actually I was asking a question, are there less coming in. []

MONICA BREITINGER: Oh, but that would be part of the reason too is they're not around. I have nothing else to say. []

SENATOR LATHROP: Well, I appreciate your thoughts and your contrast for us between the different programs. Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Monica, do you feel that since your son was overmedicated, do you think there's an abuse of overmedication in the whole system part of it? []

MONICA BREITINGER: You know, I don't see that of BSDC. I don't...except the ones...I'm on a committee to human and legal rights, and I see a lot of clients that have to come into legal and human rights. The ones that I see that are sedated are the ones with severe, severe seizures that are almost uncontrolled by medication. Those people are sleepy, but those are the only ones I see. In the community, I don't know any more. They wouldn't have many tools to use except to sedate or call the police. []

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SENATOR STUTHMAN: Okay. Thank you. []

MONICA BREITINGER: Um-hum. []

SENATOR LATHROP: I think that's it. Thank you for your testimony. Do we have...looks like we do have one more, a repeat guest. []

JACK NICHOLS: Yes. My name is Jack Nichols. I live in Omaha. We have a son in BSDC. I wasn't going to say anything. I always told my children, my older children if you're not prepared, you don't know what you're talking about, don't speak. But I'll try not to let it show too much. The two ladies that was here this morning I thought did a wonderful job being as they were contracted by Medicare, I guess, that they didn't go too far into it. But I got out of between the lines at their feeling that possibly their inspections were adequate, CMS wanted more. And I totally believe in my own mind that it's attribute to our administrations vindictive, whatever, to save money and they probably are told to find something wrong with these units. I think if you go through, check and see how many states have downsized, got rid of complete state-run mental institutions, I think you'll find there's very few left. I'm of course in the center of the woods and the trees are in the way, but I can tell you what I see. We have experienced enough, don't want to hash over it too much, but this community-based units, the closest one that would take our son was Kearney. And it lasted for a while but the police and the rescue squads and of course the neighborhood group got together and said we want these people out of here, so they moved them in town. And it wasn't very long after that they sent him to Richard Young, they went and put a mental against him and they sent him to Norfolk just because it was too much of an overload for them. We're real lucky to get into BSDC. It's been the greatest. My wife and I are scared to death that he'll be pushed into a community someplace, and like in Kearney. They'll do it for a year, the funding changes, they'll dismiss him. And where's he go there if there's no place to go? It's a real problem. We can't do it at home. In the community-based unit, our experience is if you don't feel good in the morning, you don't want to get up, you feel

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like you're sick, that don't make any difference. You get up and you get out of here because there's nobody in this house during the day. You go to wherever you go. They send them to volunteer work at Salvation Army, Goodwill. They do pretty good. But a situation comes up there, they're not equipped to handle it. I'm not saying all of them are that way because some of the staff was excellent. But the general run of the mill, they couldn't handle the situation. And these situations will pop up and if you're not experienced...I'm not 100 percent experienced, but for 30 years I can kind of see when a situation is coming up when he's getting aggravated. Our experience is they would start pushing their ideas, you do this, you do that, do it our way or the highway, and pretty soon it's the police way. Other than that, like I say, we're just scared to death that it's going to close. And what we're doing now is the situation is getting bad down there at BSDC because some of the guys that have come in years ago have mellowed out. These were a peer group my son could relate to. The community group picks and chooses and both these guys said that that's what they do because what they can handle. What's happening when the unit gets low, they start bringing in other people from I suppose different units, and then we've got to get acquainted again and build a peer group and it just doesn't work like you're in high school. These people are pretty much on a even keel. Once they get comfortable with something, things work a lot better. But then when the apple cart gets messed up, they start getting anxious. We've had three incidents here in the last month where we've went ten months without any incidents. But it's coming up. So I guess that's all. []

SENATOR LATHROP: Okay. Well, thanks, Jack. We appreciate hearing from you again. I just want to make one thing clear, when you were talking about the administration, you were talking about the President and not the Governor when you said it seems to be a vindictive thing with CMS. []

JACK NICHOLS: I used the wrong work, vindictive. Escape, maybe, plan to eliminate state-funded or Medicare-funded agencies run by a state, and our Governor also, in the communications I've done with him, is looking forward to community assignments too.

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And we drive 100 miles from Omaha to Beatrice, no less every two weeks, sometimes more, a lot more. It's worth that to us to drive that far to know that the security and the care that our son's getting is that good. []

SENATOR LATHROP: Okay. []

JACK NICHOLS: All right. []

SENATOR LATHROP: Good. Thanks. []

JACK NICHOLS: Thank you. []

SENATOR LATHROP: Any questions? Nope. All right, thanks, Jack. []

JACK NICHOLS: Thanks. Thank you. []

PATTY SMITH: Do you guys have a couple of minutes? []

SENATOR LATHROP: A couple of minutes, Patty. []

PATTY SMITH: A couple minutes. I didn't bring notes this time, but there's a couple of things that might be helpful to you so I would try. My name is Patricia Smith, S-m-i-t-h, is my last name. I'm from Omaha. I am past president of the ARC and I'm a parent and a grandparent of a son with disabilities. I just want to give a couple of answers that might be helpful. The question was asked earlier in the day if other states have closed institutions. We know that at least nine states have no state institutions. We know that 147 state institutions have closed in some 41 states and the District of Columbia and Puerto Rico. We need to know that there is a great deal of effort that has been done that could be instructive to all of you if you try to work through this. The salaries at BSDC the last two years because of a deal that came about because of the union,

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which I'm not complaining about, but the staff salaries were raised 7.5 percent each year. So in two years, it's a 15 percent increase on the salary amount. In the community-based, it was only 2 percent for the two years. There's an extraordinary...there's always been a change there, and as I understand, Beatrice is able to hire people at the second level when they even first start. So when they're talking to you about \$9 an hour and the different amount of money in the community, that's part of the problem. So that's another one. The overtime, I do not believe there's overtime budgets for most of the community-based services. That is what I have been told. They do not have overtime in their budget. At one time, Beatrice had a budget item of \$1 million for overtime. I saw it with my own eyes. That's one's done. Folks need to take...oh, the money following the person. The only thing I'm concerned about as you move people out of Beatrice, I've heard from service providers that they are concerned that after a period of time they will not have as much financial support as they get in the beginning. This is worrisome and as a group trying to figure this out, you need to look at that because if it costs \$200,000 a person at Beatrice right now and you can serve a person for \$90,000 in the community, they have real high needs. But if six months later somebody says, oh, we're going to cut it down to \$60,000, that's a problem. The thing about the service coordinators was explained to you quite well. The service coordinators do serve a function of trying to keep track of what's happening in the community. The aging parent list. I'll find the figure, but the figure is extraordinary how many parents there are over 65 years of age in the state of Nebraska who will, as has been testified earlier, are going to want more support than they're getting. It's another factor that it seems like everything you factor in is more people are going to cost more money. And this is why we're getting to my last one. Rebalance the monies because that is what is not happened. That is what the people in Washington, D.C., have begged every state to do is to rebalance their monies and to use the monies in a better way. So if the state of Nebraska is not successful at appealing the amount of money that Medicaid is going to withhold, that means then, and you guys already know this, that you're going to have to pay another \$20, \$30 million to keep Beatrice open because there isn't going to be Medicaid money there if they refuse that appeal. But if the people go into the community

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they would then be able to use their Medicaid monies. In other words, you could rebalance that money so it wouldn't be so hurtful to your budgets. The bottom line is the state of Nebraska has not come up to bat, and you as senators have been learning painfully that they have not kept even places just to keep the money going to take care of the people no matter where it was. That's it. []

SENATOR LATHROP: All right. Thanks, Patty. []

PATTY SMITH: I don't think you want question. []

SENATOR LATHROP: Doesn't look like it. []

PATTY SMITH: They're hungry. []

SENATOR LATHROP: They're hungry. []

PATTY SMITH: Thank you very much. []

SENATOR LATHROP: Thank you very much and thank you all for coming here today and we'll have hearings probably next month and we'll get the notice out to you so you can appear if you like. Thank you. []

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[]

The Developmental Disabilities Special Investigative Committee met at 1:30 p.m. on Thursday, October 16, 2008, in Room 1524 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing regarding Beatrice State Developmental Center. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Abbie Cornett; Arnie Stuthman; and Norm Wallman. Senators absent: Tim Gay. []

SENATOR LATHROP: Good afternoon, everyone. My name is Steve Lathrop. I'm Chair of the commission that was put together by the Legislature to look into the state's delivery of services to the developmentally disabled and also to look into what we generally refer to as the Beatrice situation. We've had hearings since, I think, June and taken up various topics. Today we're going to take up...this afternoon we're going to take up the waiting list. And we became aware of the waiting list as we were doing our investigation and thought it merited some discussion, so we're glad you're here today. I want to introduce my colleagues who are part of the commission. To my immediate left is Senator Arnie Stuthman from Platte Center, which is generally in the Columbus area; Norm Wallman, who is in the district that includes the Beatrice Development Center; Greg Adams to my immediate left from York; Doug Koebernick, who is my assistant; and then Senator John Harms from Scottsbluff; and Abbie Cornett from Bellevue; and then our able clerk, Beth Otto. You're all invited, those of you that wish, to testify. There are a few ground rules that I'd like to explain to you. We have sheets here and, so that Beth can keep a good record of who has testified and we can call you up if we need to get any additional information, we'll ask you to each fill out a sheet and place it in a box when you testify. That's really the primary ground rule. We are going to begin with two different people that have asked to speak, and then we'll kind of open it up, and one is going to be Mary Gordon whose LR156 group is working on the waiting list. And so I think to the extent that they've done some of their work already, we might as well take advantage of that and so I've asked Mary to testify and she'll go first. And then we'll

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have Bryan Patel, who's with the Teamsters, and they do some of the work in some of the community-based programs and he's going to testify quickly because he's got to move on and get to a different meeting. So after that, after those two have testified, please feel free to fill in the front row and if you want to testify or be heard on the subject of the waiting list, please, today is the day and we'll look forward to hearing from you. Thanks. And, Mary, we'll let you start. []

MARY GORDON: (Exhibit 1) Good afternoon, Senator Lathrop and members of the Developmental Disabilities Special Investigative Committee. My name is Mary Gordon, G-o-r-d-o-n, and I am director of the Nebraska Planning Council on Developmental Disabilities. Although the council is appointed by the Governor and administered by the Department of Health and Human Services, the council operates independently and our comments do not necessarily reflect the views of the Governor's administration or the department. We are a federally mandated, independent council, comprised of individuals and families of persons with developmental disabilities, community providers, and agency representatives that advocate for system change and quality services. I have been invited to speak to you today about the council's activity related to the waiting list for DD services. Legislative Resolution 156 of the First Session of the One Hundredth Nebraska Legislature charged the Department of Health and Human Services to establish a work group to: one, submit recommendations for a strategic plan to incrementally reduce the number of persons on the waiting list for developmental disabilities to meet the intent of the Legislature; two, consult with the Department of Health and Human Services to review and make recommendations to any revisions to the rate methodology; and three, submit the work group's recommendations on the strategic plan and revisions to the state methodology in a report to the Medicaid Reform Committee, the Legislature, and the Governor. After a discussion with Senator Johnson, the department asked the Nebraska Planning Council on Developmental Disabilities in December of 2007 to oversee the work group and its activities. We're a very small program. There's really only two professional staff and, as a result of my own cancer treatment and the need to go through the state bid process to ensure that a neutral

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facilitator for the work group was elected, the first meeting did not occur until October 1. Three additional meetings are scheduled and the report will go to the council for their review and approval in early December. The final report is due December 15, 2008, and we will hopefully get it to you all first and then to the rest of the Legislature. I have given you a copy of a handout given to the work group at their first meeting. It's titled "Understanding the Waiting List," and it was prepared by the LR156 work group facilitator using data supplied by Health and Human Services. First of all, I'd like to share with you some general things that the work group is looking at. First, the waiting list itself is very complicated and not always understood the same by everyone. In Nebraska, individuals with developmental disabilities or their families may put their names on a registry to indicate that they may need services. When they do this, they are asked for a date on which they will need the requested service. They can choose today's date, or the date they put in their name, or a future date. The term "waiting list" refers to the subset of people on the registry who are past the date that they requested services. However, since most people know that services are not available when needed, they may select a service date to allow for this delay. For example, if people need services in 2013, they may record their service date as 2008 to try to ensure they will get services when they do need them. Of course, this means that the actual number of persons on the waiting list may be inflated, and the DD Division reported to the work group that almost 30 percent of the people offered services turned them down and postponed to a future service date. So to just hopefully clarify, it's not that those numbers are wrong or when I said inflated, I didn't mean they're more. It's just that the past...the ones on the waiting list may not really be waiting. They may need them in the future, but they put their name as of that date just so they can make sure they get them when they do need them. Under the traditional DD Medicaid waivers, which I know you all have heard about so I'm not going to bore you with it, but there are basically three types of services that individuals are waiting for: day services, which are typically vocational but may be some others; residential services; and respite. The majority of individuals on the waiting list are waiting for residential services. As of July 1, 2008, there were 1,865 persons waiting for services. Of these, 1,628 of them were waiting for

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residential services, and this is primarily because Nebraska has offered day services as an entitlement to Nebraska youth who graduate from a Nebraska high school at age 21 since 1993. As senators, you may hear from two other groups that have concerns about services they need, but these individuals are not on the waiting list that we are discussing. The first group is individuals who have been approved for the needed units of service but, because of where they live or the difficulty of finding a provider willing to serve there...serve them, are unable to make use of all the units that have been authorized. An example of this is individuals with complex medical needs living in rural areas. Their medical conditions do not permit their being transported to a workshop or day program, and an appropriate person to come to the home is not available. Although these individuals are not on any waiting list, the Developmental Disabilities Division is able to identify these people since they are billing for less than authorized hours. A second group of individuals are those people who are receiving a service but the authorized hours are less than the assessment has determined is needed or less than some members of the team feel is needed. These are the underserved. This group is much harder to identify and is not kept on any waiting. Our work group is looking at the waiting list but also discussing these other two groups, as any system change will have an impact on all of them. Obviously, we've only had one meeting so it's too early in the process to have recommendations for you, but I will share with you my sense of what the group is considering. Obviously, there will be need for additional funding. Even if we believe that 30 percent of the people on the list will postpone their request when offered a service, that still leaves a large number of individuals, over 1,300, that will accept. However, funding is not the only answer. The same need for qualified direct service workers which you have been hearing about in relation to BSDC exists in the community. Low staff salaries and training issues are identified problems. Providers have indicated that it takes about one person hired for every one person served, so that will mean a hiring of almost 1,300 people to serve, or 1,800 if you look at the full list. The actual labor pool out there for that many individuals is going to be a real challenge for our state. Accessible housing and city ordinances can limit the development of traditional residential settings, such as group homes. As a result, the work group is

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looking at more flexible models of service delivery to maximize resources and ensure the programs are achieving the best outcomes for people's lives in the most cost-effective way. This includes the community supports waiver and Nebraska's high-cost expense in using habilitation as the primary waiver service. As far as training, the Nebraska Planning Council is making grant funds available to DD providers to pilot the Collect of Direct Support--a national, Internet-based learning program for direct support staff. It has been proposed at the LR156 meeting that changes in the way the state manages and prioritizes the waiting list may make it a more useful tool and enhance capacity. The method of paying for DD services is also being reviewed to determine its impact on the waiting list and if changing this rate methodology could help decrease the waiting list and use current resources more effectively. As you can see, there's not an easy answer to addressing the waiting list. Our work group is identifying issues, including reviewing past recommendations, to make current recommendations that Nebraska can use to decrease the waiting list. Just want to mention, prior to my coming up here, Senator Lathrop had asked about data. We do have quite a bit of data we've gotten from the Developmental Disabilities Division on the waiting list and I will share that with Doug and he, obviously, will be able to share it with you all. Just didn't want to overwhelm you with paper today as we...because it is a lot, but we're trying to put it in an order to understand it. And I thank you, and if anyone has any questions I'd be glad to try to answer them. []

SENATOR LATHROP: Sure. Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Mary, thank you for coming and giving us this information. Can you give me an example of an individual with developmental disabilities that would need services, like you state, in 2013? Why would you request it at that time? Give me some type of an example of why that would be. []

MARY GORDON: Okay. For example, I may have a 16- or 17-year-old son or daughter or a 25-year-old and I know that I want a group home. I'm going to retire, move out of

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the state, something, so for some reason I know that I want a group home and, in my mind, I'm thinking, well, by the time 2013, either they'll be 22 or 23, my other children have moved out by then, that's when I'm going to want a group home. But I know that when that time comes and they are 23 or 24, there might be a five-year list. It might take five years to get it. So I go ahead and put my name on the list saying I need it now--even though my child is only 16, or 17, or 25, or whatever--then when that...hoping that when that time comes, I will need it. What sometimes happens, Senator, is that when that time comes and it is offered to me, things may have...my life may have changed. Suddenly my 24-year-old, you know, we're not moving, I'm not retiring, they're in good health, I'm in good health, they have a job and so everything is fairly settled at home and so I may say, no, I don't need it now, maybe five years from now I may need it, so then I'll put 2018 on the list. So I don't know if that... []

SENATOR STUTHMAN: Yes. Yes, that helps me a lot. It's you're planning for the future... []

MARY GORDON: Right. []

SENATOR STUTHMAN: ...for your own health and age and everything. But, you know, it may not occur, but when you decide to do that, it might not be available for another five years. []

MARY GORDON: Right. []

SENATOR STUTHMAN: So, okay. Thank you. []

MARY GORDON: So you might project out,... []

SENATOR STUTHMAN: Yes. []

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MARY GORDON: ...thinking I'm going to...I really think I need it in ten years but I'm going to say five years or this year, just hopefully. []

SENATOR STUTHMAN: Okay. Thank you, Mary. []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: Senator Adams. []

SENATOR ADAMS: Mary, if I might, I'd like to clarify something. I heard you say the number is inflated, and you did a good job of explaining why that might be. Then I heard the number 1,300 and I heard the number 30 percent, and maybe they have nothing to do with the answer, but if we could...if you could deflate and get us to an approximate number of how many people right now need services, what might that be? []

MARY GORDON: I would say that it probably would be...the list right now with the 1,800, if you take off 30 percent, that's about 1,300. []

SENATOR ADAMS: Okay. []

MARY GORDON: So that's... []

SENATOR ADAMS: Okay. []

MARY GORDON: ...that's where I came up with the 1,300. []

SENATOR LATHROP: I do have a few questions for you, Mary, if I can. []

MARY GORDON: Oh, sure. []

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SENATOR LATHROP: We had some discussion about the waiting list previously and if I understand what's happening in the state of Nebraska with respect to the services provided to adults is that if you have a school-age child, which would be, in Nebraska, under 21, the services that are provided to assist in the education, which might include physical therapy... []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: ...and occupational therapy and those kinds of things, that's all going to be provided by the school district. []

MARY GORDON: Right. []

SENATOR LATHROP: So for the...for those who have developmental disabilities who are not yet 21, their needs are being met either with Mom and Dad at home plus the school district. []

MARY GORDON: Yes, primarily. Yes. []

SENATOR LATHROP: Generally true? []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: It is when those high school seniors,... []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: ...and it's about 200 in number, when they graduate, we have...we've somewhere along the way put them at the front of the line and they get to become the next 200 people to get day services. Is that true? []

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MARY GORDON: Right, yes. []

SENATOR LATHROP: And we have in Nebraska about 200 people leave the system through attrition. []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: Yes? []

MARY GORDON: Well, yes. []

SENATOR LATHROP: Okay. []

MARY GORDON: They told us about 145, so that's about right. []

SENATOR LATHROP: So we basically have as many people leaving the system as we do high school seniors or graduating high schoolers. []

MARY GORDON: Right. []

SENATOR LATHROP: So do we make any ground on the list at all? Is the list static, and people who are on it that are not folks who are just reaching 21 and graduating from high school, those folks, are they just stuck on that list? []

MARY GORDON: Yes, right now. The last time, I believe, that people got off the list was in 2006 and we had...some of you may remember there was some money set aside from the tobacco money and not all of that was spent and so that tobacco money was the last money that actually...what happens to those people, they're stuck in one. They are stuck, but what the...kind of the safety net, but it's not the best, is they do have a

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system, what they call priority one. I call it emergency or crisis. Basically, if my parent is caring for me and has to be hospitalized or some...or something happens, then those individuals get bumped to the very top, will get additional hours. []

SENATOR LATHROP: So as we look at the list and the way the state is managing the list currently, you're there unless you abandon your ward. Whether that's your son and daughter or you're the guardian of them, you have to essentially abandon them, make them a priority one, before they're going to get off the list and start getting services. []

MARY GORDON: Right. And abandoning is not easy. []

SENATOR LATHROP: That's where we're at. []

MARY GORDON: Yes. But yes. []

SENATOR LATHROP: That's where we're at. Your estimation was that 1,865 families or persons are on the list; 1,628 of those are waiting for residential services. But even the...we have approximately 200 people leaving or 145 people leaving. Some of those are getting residential services but we move over the graduating group and they get day services and not residential services. So the number of people we're serving for residential services is getting smaller. Would that be true? []

MARY GORDON: That would be true. And just...I'm sure you know, the day services are much cheaper, obviously, than residential. Residential group homes are probably the most expensive service right now. And so what happens is, as those people who leave or die or move out of the state and drop off of residential, there's two things that happen. One is that money, because you're basically putting those 200 in to "day," which is a less costly service, that any savings you may have then goes in to pay for the priority one, for those emergency people. So that money is moving over there. The other thing that happens, and we've heard it in our work group and I'm sure you may

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hear it as well, what happens is that loss of people leaving is creating a real problem with our providers, because the providers have...you know, they may have a home where three people or four people are in it, one person leaves or passes away or something happens, they may not get funding for someone else to come into that home. So basically, they have to either move everybody out to find new places for them to live where they can get enough hours for them, or kind of do an upset-the-applecart kind of thing to try to put together a group home setting. But...so there's kind of two...actually, there's many more effects, but that's the two that (inaudible). []

SENATOR LATHROP: That's a couple of the consequences. []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: I want to ask you about your group so that I can understand and I make sure we don't... []

MARY GORDON: Sure. []

SENATOR LATHROP: ...expend our energy doing exactly what you're doing. You are, through the LR156,... []

MARY GORDON: Six, right. []

SENATOR LATHROP: ...charged with exploring or having a complete understanding of the waiting list, and do you then also issue a report for a strategy to reduce the list down to zero or something? []

MARY GORDON: Yes. Yes, that is what our...what we've been charged to do. I don't know how many years till we get to the zero, but we will be...we will be coming up with recommendations on how to reduce it. As you know, the statute actually says that it is

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the intent of the Legislature, and it makes a reference to that, to eliminate the waiting list by 2010. Well,...so... []

SENATOR LATHROP: It's going to be a lot of work. []

MARY GORDON: It's going to be a lot. (Laugh) We've got a lot to do in the next three meetings. No, I'm just kidding. But I do think that we will be making recommendations on a plan and some ideas, because I think...and this is just my feeling, senators. I think that all of us recognize that probably we can't do things the way we're doing things and serve 18...because even if there's...you all...even if the Legislature and everyone said, we're going to give you the money to serve those 1,800 people, next year there's going to be more. Every...I mean, there...and so I think that we have to think about maybe our traditional system, our focus on habilitation. I mean the fact that habilitation, which is a very costly service, is our primary way we deliver community DD services in our state. []

SENATOR LATHROP: Are you suggesting that we might have to sacrifice habilitation in order to serve more people? Because it seems to me... []

MARY GORDON: I'm not sure... []

SENATOR LATHROP: ...that that's CMS's...I mean that's our primary responsibility for people in 24-hour care, isn't it? []

MARY GORDON: Well, yes and no. There are also services that other states are using with their Medicaid waivers for people in community-based that are not just habilitation. Habilitation is as you've heard; we relate it to active treatment. But there, you know, but there are other services. Transportation is a service. Community support, having people, you know, be more...there are less costly services. Right now, for example, and transportation is a Medicaid-approved service that could be written into the waiver. We don't have it, but if someone has a job in the community we basically...but need

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transportation there, we have to bill it as...a provider has to bill that as habilitation to take that individual to their job. Now, granted, they may be talking to them about a job and visiting with them about a job, but to pay \$25 an hour for someone to take someone to their job may not be the most effective use of our Medicaid dollars. I'm still talking about using Medicaid waiver dollars. []

SENATOR LATHROP: Right. []

MARY GORDON: I'm not talking about get...but I'm just saying possibly expand the options of services that we do pay for under that to some less costly ones. []

SENATOR LATHROP: Okay. Any other questions? I don't see any. Thank you very much for coming down. []

MARY GORDON: Thank you very much. []

SENATOR LATHROP: We'll look forward to your information and your report. []

MARY GORDON: Okay. Certainly. Thank you, senators. []

SENATOR LATHROP: Bryan. []

BRYAN PATEL: Good afternoon, senators, Chairman Lathrop. My name is Bryan Patel. I'm a business agent with the Teamsters Local 554 in Omaha, Nebraska, and my function there is to negotiate and administrate collective bargaining agreements. One of the groups of employees that I represent is the Eastern Nebraska Community Office of Retardation, known as ENCOR, and what they do is they provide community-based services for the developmentally disabled people. The bargaining unit I represent consists of about 400 people, 200 or so in the vocational side and another 200 in the residential side. Biggest benefit that we've been able to negotiate for these folks is

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medical insurance through Central States, which is a Teamster fund, not-for-profit. We've been able to get them a very good insurance plan. It's a 90/10 plan, \$250-\$500 deductible, vision, dental, that type of thing. One of the biggest pitfalls that we have is the extremely high turnover rate we have there and that is probably a result of what the pay is. The starting pay rate there is \$10.35 an hour, and if you do the numbers on that, at the end of the month I'm coming home with about \$1,200, and that, you know, in my opinion, is not a living wage. It's very difficult to sustain a household, let alone raise a family on that kind of money. I see two types of people, basically, that are employed there, and the first type of person I have all the respect in the world for. They do it because they want to do it. They're obviously not doing that type of work for the money. They do it because they want to do it. And the other people, the second category of people, it's really about all they could find. You know, it's just people looking for a job and the attraction for those folks for that job is, if I'm in the residential setting, I'm in a group home and I could be working, for example, a 40-hour week and I may not see a supervisor for 1 or 2 hours of that week, so I'm pretty much on my own, and that's probably where the problem comes. The funding levels being what they are, not only are they understaffed, the front-line supervisory people are understaffed as well. So if I get hired on as a residential associate, I will get some training in my orientation, some book training. But as far as hands-on training, I'm really not getting very much, if any. Pretty much sent out to the group home and if you got any problems, call me, that type of thing. That, in my opinion, diminishes the level of care that the people are receiving, and that's what it's about. You know, that's what the folks are here to do. I think another further end of the problem is the recent turn of events, I'm sure you're all aware of in Beatrice, has resulted in additional numbers of the DD people being discharged into the community-based programs and it's just putting a further burden on an already burdened system. Basically, in conclusion, the folks that I represent, you know, they have a lot of hurdles. They have substandard wages, the high turnover rate, the training is just really not there for them. That coupled with the increased numbers of people being injected in the system, I think, you know, we need to look down the road and anything that this committee, in conjunction with the Legislature, could do to appropriate

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the funds to get better wages and better working conditions for these people so we can retain good people to do these jobs rather than just cycle through periodically the same people over and over. Because ultimately, the people that suffer at the DD people and that's not what we want. So it's really all I have. Any questions of me? []

SENATOR LATHROP: Thanks, Bryan. Any questions? I don't see any. []

BRYAN PATEL: Great. Thank you for your time. []

SENATOR LATHROP: Thanks for coming down today. Yeah. Rich. []

RICH SECOR: Good afternoon, senators, Chairman Lathrop. My name is Rich Secor, S-e-c-o-r. I'm president of a group called Village of Promise in Omaha, Nebraska, and with me today, besides myself, are five individuals from my group. We are a 17-member group that consists of various caregivers and community volunteers in Omaha, and our mission is to serve adult individuals with cognitive disabilities, those individuals that have chromosomal disorders, such as Down's syndrome, autism, and other disabilities. Our mission is to develop an integrated village, like a Boy's Town, that would ultimately one day have residential buildings, employment opportunities, recreation opportunities, as well as educational opportunities for adults with cognitive disabilities. We're an alternative to dependent living at home or dependents living in group homes. A need for our care is growing because of aging demographics. In many cases, adults with cognitive disabilities are outliving their caregivers. The longevity of their lives is increasing. The population is growing, by some of the numbers that we've been studying, and that we have estimated that there are roughly 7,900 individuals with disabilities, cognitive disabilities, in a four-county area--Washington County, Douglas County, Dodge County, and Sarpy County--and that population is expected to grow to 9,200 in the year 2020. The need...consequently, the need for long-term residential, employment, recreational care is growing, not only because of the changing demographics but also because the population is growing itself. Such care is very

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expensive, as everybody knows. Our preliminary financial models indicate that the care for an adult with cognitive disabilities ranges anywhere from \$4,000-\$6,000 per month living outside of a home, outside of their personal residence, if their caregivers are no longer caring for them. Our surveys indicate, in our surveys with our various caregivers, that our caregivers are willing to spend anywhere from \$500 a month to \$1,500 a month toward this type of care. Consequently, there appears to be about a...anywhere from a \$2,500 to a \$4,500 a month void in terms of fulfilling the need for this care. We're very concerned about being able to fill this gap and to fill this void. We're not here today to talk about the merits of our village, and what our dream is, is to have this kind of a living environment for adults with disabilities. We're here today because we're very concerned about the ability for these individuals to be cared for in the long run. Our group today--besides myself there are five others--we're going to give brief testimony today of our own personal situations and we cover the gamut from Terri Lynch, who's a caregiver of a 35-year-old son, to Jason Tonjes, who has a daughter that's 3 years old who is just planning for the future for his daughter. So with that, I'd like to turn over to Terri Lynch and she can give her testimony. []

SENATOR LATHROP: Rich, before we let you get away,... []

RICH SECOR: Oh, okay. []

SENATOR LATHROP: ...let's make sure there aren't any questions. Anybody? I might just ask a couple just to clarify your testimony. You are with the group, Nebraska Village of Promise, and that's actually a group of parents and not a business. []

RICH SECOR: Correct. []

SENATOR LATHROP: Is that right? And... []

RICH SECOR: Parents, and we also have some community volunteers that are part of

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our committee. []

SENATOR LATHROP: And your...we've had some discussions about this... []

RICH SECOR: Uh-huh. []

SENATOR LATHROP: ...so I have a little bit of background on it from our previous discussions, but basically your group of private individuals are interested in developing, with your own money, a village, kind of a new concept in the Omaha area is where it would be, which would provide a community environment for people with developmental disabilities. []

RICH SECOR: Yes. If you could kind of visualize what Boy's Town does, that's exactly kind of what the model that we would like to have, only instead of serving troubled teen, essentially, we're serving adults with cognitive disabilities. []

SENATOR LATHROP: Okay. And you're here today just to kind of offer your idea in the face of sort of our inspection of the delivery of developmental disability services. []

RICH SECOR: Correct. Yeah, we're very concerned about the financial means to support the adults with disabilities with this kind of care. And again, it's pervasive, whatever kind of care that these individuals get, whether or not they continue to live at home, whether they live in group homes, or whether they live in a village like what we have planned. It's all about the money and there's just not enough, unfortunately. []

SENATOR LATHROP: Right. Okay. Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. Yes, is this patterned something like after Sheldon (phonetic), Iowa, then, you know? []

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RICH SECOR: Yes. Yes, there's a couple of these. Actually, I'm told there's five or six of these kinds of communities in the state of Iowa. Opportunity Village is another one in Clear Lake, Iowa. Uh-huh. []

SENATOR WALLMAN: Thank you. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Rich, you...none of this in place yet. []

RICH SECOR: No. []

SENATOR STUTHMAN: So it's just anticipation and trying to get...trying to establish something if there's...and you see there's a need for it, so... []

RICH SECOR: Correct. []

SENATOR STUTHMAN: So but there's nothing in place. You have no record or anything like that yet. []

RICH SECOR: No, there's not. Our plan is to build facilities with private money. However, we would need public money to make the operation work, simply because the caregivers don't have \$4,000 to \$6,000 per month to help support what it's going to take per individual. []

SENATOR STUTHMAN: Are you thinking of just putting something in, you know, in the metropolitan areas, or are you thinking of anything out in the rural part of the state? []

RICH SECOR: As you can imagine, it's a huge undertaking just to get the first operation

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going. But, yeah, potentially there could be some satellite locations spread across in the rural communities potentially, yes. []

SENATOR STUTHMAN: Okay. Thank you. []

RICH SECOR: You're welcome. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: Oh, thank you, Senator Lathrop. What would your budget be as you look at this program? What kind of budget would you anticipate? []

RICH SECOR: Well, it depends upon the number of individuals served and also depends upon what individuals need in the way of services. []

SENATOR HARMS: So let's just take it in general. What...how many people would you want to serve or capable of serving, as you look at this, that would be realistic so I can get a fix on how you would price that out budgetwise. []

RICH SECOR: Well, right now we have a business plan that we're just finalizing and it's kind of a phased approach and the first stage would be to serve 20 individuals. And with serving 20 individuals, I believe our numbers anticipate a monthly cost per individual, about \$6,000 per month. So it's akin to assisted living and/or nursing care for the elderly. As we achieve economies of scale by expanding the village, building more buildings, also increasing the population, there will be economies of scale and there will be some efficiency with regard to being able to spread a lot of the overhead. We think, ultimately, by the time we're serving in excess of 50 people or so, that we think we can get those monthly costs down to probably closer to \$4,500 per month per individual. We don't know how big the village is going to be. We want to start it off small and be able to manage it effectively with the initial 20 people. Someday we'd love to have it as big as

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many a couple hundred individuals. In Sheldon, Iowa, and in Clear Lake, Iowa, at the Opportunity Village in Clear Lake, I believe they're serving in the neighborhood of a couple hundred people in their various villages. []

SENATOR HARMS: So as you look at maybe 50 people, what kind of staffing would you have? []

RICH SECOR: I don't really recall the allocations offhand, but I would tell you, I think with our 20-person model, I think we've got about a 2 to 1 staffing ratio, I should say 1 staff person per 2 individuals. []

SENATOR HARMS: What educational level will these people have as staff members? []

RICH SECOR: Well, they, obviously, have to have some experience. We don't want to hire anybody that doesn't have experience. There would probably be some kind of a mentor relationship with regard to individuals that would need to be trained. We really haven't worked out the specific hiring practices, the various staff requirements. You know, we've got a business plan that we're finalizing that addresses how potentially we would fund-raise for private dollars to build the initial two or three homes to serve 20 individuals. And I do want to make a point that we anticipate all the real estate, the land acquisition, the construction of buildings and so forth coming from private dollars, perhaps from caregivers, perhaps from foundations, from private individuals. It's the operation dollars that are critical and, as I mentioned before, it appears that caregivers, as a general rule, can only afford maybe about 25 percent of those dollars. []

SENATOR HARMS: I want to go back to your staffing again, because one thing I've at least learned from the Beatrice side is that staffing is critical, and having the right educational level is critical, having the right kinds of staff development is critical. And just to be able to hire people and bring them on, into your system, is not going to work well. So that's why I was asking about the educational level, what your projections are,

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what type of support are you going to have. Are we talking about doctor's degrees? Are you talking about master's degrees, associate degrees? I mean this is really important to be able to treat the kind of clientele you're talking about, so that's why I'm interested in knowing what you're thinking about in regard to that particular area. []

RICH SECOR: Yeah, we don't, Senator Harms, there's no question we don't want to experiment and, you know, we want to be successful because we don't want to be a disserve. We don't want the program or the project to fail because we want to be able to grow it. And those staffing recommendations certainly are very important and we would certainly implement them. []

SENATOR HARMS: Thank you. []

SENATOR LATHROP: Think that's it. []

RICH SECOR: Okay. []

SENATOR LATHROP: Thanks, Rich. I appreciate your testimony. []

RICH SECOR: Terri, I'll call you up. Thank you. []

TERRI LYNCH: Senator Lathrop and committee, I'm here with my son David, he's a Down syndrome, and with my husband Joseph. I'm present today to really just talk about my situation. David is 35 years old. []

SENATOR LATHROP: Hey, Terri. []

TERRI LYNCH: Yes. []

SENATOR LATHROP: Why don't we have you start with your name for us so... []

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TERRI LYNCH: Oh. Terri Lynch. []

SENATOR LATHROP: Okay. []

TERRI LYNCH: T-e-r-r-i L-y-n-c-h. []

SENATOR LATHROP: Terrific. Thank you. []

TERRI LYNCH: And David is David Luers, L-u-e-r-s. Even though David is 35, he has a mental age of about 2 to 4. I wanted you to see him as a real person, to put a face to the situation. He's not somebody sitting on a shelf, waiting for something to happen. David lives at home with us and we are his guardians. He was born and diagnosed with Down's syndrome at birth. They suggested he could go to the Beatrice home or we could take him home and see how he does. We took him home. He attends the Cass-Sarpy County workshop at...ENCOR's Cass-Sarpy workshop during the day and he does very well. He likes it. He gets on the bus; he rides, unfortunately, a very long period of time, about two hours a day. But he hasn't always had transportation, he hasn't always had services. After...going back to his earlier days, I just want to remark, too, that Nebraska has always been a model and a leader in the early childhood intervention, and he did have early childhood intervention and did quite well when he was in the school system. But I really feel that Nebraska has fallen behind when it comes to serving the adult developmentally disabled citizens. For example, he waited three years for availability to get into a workshop and there was a time where there was not transportation for him. It's not like we lived in the boonies. We lived (laugh) we lived in Bellevue. We were paying approximately \$25 per direction per day and his private transportation exceeded his SSI payment. Now he did finally get transportation and we are extremely grateful for that. But during the three years, of course, he did lose some ground and they need to have a place to go and stimulation. David has been on the waiting list for Medicaid waiver or permanent residential care for approximately ten

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years, or so I thought it was ten years. And I, you know, Mary mentioned that we were at...we should have been asked when we want him on the Medicaid waiver, when do we want that to happen. I personally do not recall being asked when that should happen. But I did find out, when I talked to his caseworker last month, that he had been bumped off the list. Because I said, where is David on the list? And he said, well, he's not on the list. I said, well, how can that be? You know, I remember this conversation at least ten years ago, maybe even longer. And he said, well, you know, technically David has residential care. And I said, I don't understand. Well, David has his workshop during the day and then he goes to a group home for one to two hours, usually it's about an hour and a half, so that we can work or be able to...I mean, we just can't get him at 3:00 every day, and he said that's residential care. I said, well, I was shocked. How can this be a substitute for 24-hour-a-day permanent living? Why didn't somebody tell me about this technicality? It's a technicality. Is this how the state of Nebraska is reducing the number on the waiting list? This is absurd. Let me tell you about another technicality. David is technically a ward of the state. The state of Nebraska is really not providing David with care and I think the state should be ashamed of this waiting list. Nebraska has been a leader in the past, and it's not. And I don't really want to get into this technicality but just to really emphasize and be clear that the problem is lack of availability, and the availability is related to lack of funding. That's what it boils down to. There are beds out there, there are places, but they're not funded. David is nonverbal so we are his voice. We're interested in Village of Promise because it offers...it offers something we think that would be good for David. []

JOSEPH LYNCH (?): There are many parents in this room. We must make decisions that we believe are good for them. We feel that we are limited in the type of residential care that's available, either in Beatrice State Home or the group homes. We are interested in the new concept for residential care. We do feel that Nebraska Village of Promise would be one that may be the best choice for David and people like him. It's really apparent there's not enough residential care money appropriated for special needs children. We're asking today for consideration for those dollars, that they follow

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our children to a provider that has a model of care to assist him in reaching his potential in a community-living or assisted-living setting. Most other states have this model of residential care. Why doesn't Nebraska? We're asking you to be open to new, innovative ideas and to appropriate money for people like David. You want me to read it? In the end, if we might be philosophical for a moment, we believe we are judged not only by how many bridges and ball parks we've built but by how we take care of our most vulnerable citizens. Please consider our situation. Please give David and others like him a chance to meet their potential with dignity. Thank you. []

SENATOR LATHROP: Thank you, both, very much. Let me make sure there aren't any questions before we let you get away, Terri. Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Terri, from what you've stated, the fact that David had been getting services, was doing very well and then now he's not having a place to go, is that correct? []

TERRI LYNCH: No, he had a gap between the end of high school. He had to wait three years to get day services. And I thought he was on the waiting list for residential care. Apparently this technicality bumped him off. So I asked to be...he be put back on the list and they said, well, that's not possible because he's getting those...that hour, hour and a half between 3:00 and 4:30, and they're calling that his residential care. []

SENATOR STUTHMAN: Which is only a minimum part of what is really needed. []

TERRI LYNCH: Yeah. And that, by him having that hour, hour and a half, we're able to care for him. It was really a bridge to help us while we were waiting for the permanent residential care. []

SENATOR STUTHMAN: Uh-huh. And how...what was the time frame for that, that you've been receiving just this hour, hour and a half? []

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TERRI LYNCH: Just a few years maybe. []

SENATOR STUTHMAN: Just several years. []

TERRI LYNCH: No. No, maybe five. []

SENATOR STUTHMAN: Five years. Okay. Thank you very much. []

TERRI LYNCH: Okay. []

SENATOR STUTHMAN: You had a very good study. []

SENATOR LATHROP: Senator Adams. Oh, I'm sorry, Terri. We're not done with you. []

TERRI LYNCH: Okay. []

SENATOR LATHROP: Just a few more questions. []

SENATOR ADAMS: Terri, you may have already answered... []

TERRI LYNCH: I want to run and hide. (Laugh) []

SENATOR LATHROP: No, you're doing a great job, by the way, and we're glad you're here. []

SENATOR ADAMS: You may have already answered this, but what was David's age when he left high school? []

TERRI LYNCH: Nineteen. []

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SENATOR ADAMS: Okay. So we had that gap between 19 and 21. Okay. Thank you. []

SENATOR LATHROP: I think that's it. Thank you very much for coming down today. []

TERRI LYNCH: Okay. Thank you, Senator Lathrop. []

JOHN HERDZINA: Good afternoon, senators. My name is John Herdzina. I'm from Omaha. And, first of all, I would like to say, and I mean this sincerely, thank you for taking up this issue. I think you've got a real opportunity to make a difference in people's lives. And, man, if I was able to serve on the senate, in the senate, something like this, I'd be fortunate to take up. So thank you for that. I have two children with special needs. I have three children, total. Lived in Omaha my whole life, married to my wife Jacqueline (phonetic), and when my oldest son was born, his name is Grant, it came up before he was born, the diagnosis was terrible, that he was going to have all these problems, mental and physical and everything else. And, you know, we went through the agony of making the decision and said, hey, you know, we believe in this life thing, pro-life, so we had the child. Turns out I had the special needs developmental disabilities. So if you meet this kid today, you know, he's beautiful, 26 years old. He's went through Westside special needs program, special ed program, and in a minute I'll tell you a little bit more about him. But anyway, the doctor is telling us, hey, it was a chance in ten million that that happened. We can't even figure out what it is genetically so don't...it's not going to happen again. Have our second child who I'm proud to say is a...graduated with honors from Creighton University and is employed, doing well. Had the third child and the third child has the same disability as the oldest. She goes through special ed at Westside and this is where...I mean you guys are taking up...excuse me, Senator, you people are taking up such a difficult issue. There's so many things to talk about. I want to try to keep it short and to the point. But, you know, when the Senator Lathrop talked about the transition program when you're 21 and you get out, well, that Individuals with Disabilities Education Act that was mandated by the federal government says, yeah, you've got to

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do this. So when they're getting all this socialization and education and companionship and care in school, it is a wonderful thing--and I don't know outside of Omaha how good it is but the Omaha school districts and areas do a great job at it--but then when they graduate, it's over. And the problem I'm having when I hear about the list is that, in all our lives, we plan. We like to plan what's ahead of us. I know man plans and God laughs, but I like to plan ahead at what's going to happen to these kids. So I put them on the waiting list for residential well before they got out of school and hoping that they get what they deserve, which is like any, quote, normal person. They have a choice whether they want to go to school, and if they go to school they go away to school and they're independent and they begin to live on their own. My plan for them was just that. They could live with me forever. You know, that's what life is all about. You take care of your own and that's my vocation in life, to take care of these kids. But God forbid I have a heart attack tomorrow. One of the inevitable is going to get me. I'm getting older, sick, disabled, feeble, die. You know, sooner or later they got to go. I just don't see how we let these people exist without planning for where they're going to be. Why should crisis drive where they end up living and who they end up living with? And that's why I'm trying to get across to you that the importance of getting these people off the list is so critical. Without the assistance, they can't...right now they both want to live outside the house. They see their friends living independently. I just can't...I can't afford on my own to pay for them to live independently. Anyway, that...I just...decisions being made by crisis don't make sense to me. Yesterday I found out that I was denied again, because I wanted to move up on what Mary testified to, that priority, getting priority on the registry, so I applied for priority on the registry because Grant has been on this thing for I don't know how many years and just not getting anywhere. So we had made out the application and everything, caseworker called me yesterday and said, you've been denied. I said, well, why, other than there's no money, the standard answer? And he said, well, because they aren't being abused and there's no crisis here to where they're in imminent danger. I said, well, of course not. You know, they're with my wife and I. But what basis is that to turn them down? They said, well, under the way the rules are now with the list, it's ruled by crisis, not by...and I forget the terminology Mary used with you

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all about having a date certain down the road, date of choice. And he said, there is no such thing right now, so it's all by crisis. Well, again, I think that says it, in and of itself, what the real problem is. You know, it's kind of like this Safe Haven Act we have is kind of where we are. People with children under 19, this act, you know, they drop this person off and the state has got to take care of them. Well, I told that to my caseworker. I said, well, what if I just said I threw Grant and my daughter Gabriel out; she's your problem? And he laughed, he says, well, one, you're not going to do that and, two, if that happens I'll deal with it. So that's the severity of the situation, senators. I know this funding is a huge issue. Thank goodness we now have a surplus. But that money really is needed to take care of these folks on this list. And Senator Lathrop brings up an excellent point about whether or not there's more coming on as there are going off, and that's a tough, tough issue to deal with. But that's really all I have. I think I got the point across. []

SENATOR LATHROP: Thanks, John. We'll see if there's questions. Can you tell us how long Grant has been on the list, John? []

JOHN HERDZINA: Well, he graduated. He's 26. He's been on the list probably three years before but, you know, he...so he wouldn't be able to have lived outside the house until after he graduated. So I'd say effectively over five. []

SENATOR LATHROP: Five years. And what you're being told is, unless he becomes a priority one by essentially being abandoned, you're on the list perpetually. []

JOHN HERDZINA: Yeah, he's not going to live anywhere else. And I have appealed that and it will come up here to the Health and Human Services people but, you know, I've been told already that I'm not going to get anywhere. And I submitted...I had them both tested with the psychiatrist and the psychiatrist wrote letters to the coordinator and the supervisors and said, hey, these people need to be on their own, you know? They have some mental capability there and they want to be independent, and in order for

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them to mature and nurture and be a benefit to society they need to be out there. But it didn't do any good. []

SENATOR LATHROP: Okay. Thank you very much for your testimony. []

JOHN HERDZINA: Thank you all very much. Appreciate it. []

JEANNE PATRICK: Thank you, Senator Lathrop and all of you. My name is Jeanne Patrick, P-a-t-r-i-c-k, and I come here as a grandmother, speaking for my grandson Justin. Justin is 19 years old. He also graduated from Westside. I reminisce back through his younger years, he had really good social contacts and services provided and was relatively a happy, happy young man. He's severely impaired. He's in a wheelchair. He has to be dressed every morning. He has to be bathed. He can dress...he can go on and off of the toilet in a fashion, and feed himself a cheeseburger and fries, but he is very impaired. But intellectually and mentally, he's not challenged. He's an intelligent, bright young man. He's also very depressed. He's...all the years he's gone through school he was with his peers, very well accepted at Westside. You know, I couldn't have asked for a better school district. They actually moved from another school district because of the money available at Westside. But...and my son went out of the work he was in, doing his self-employment, so he could be available after school. I'm also self-employed so I, throughout the years when Justin was young, many times we were scurrying to meet the bus at 3:00. None of us were working our regular schedules so we, more than all of us, you know, tried to give Justin the best life that he could possibly have. There are two other grandchildren. They're in their teens. They have put forth a valiant effort. We've all given our best to Justin and the best that we could possibly have for him. But here we are. You know, we're out of high school and, like Mr. Herdzina, there's nowhere to go. There's a real, real gap. And when he says, Grandma, you know, well, it used to just bother me when he'd say, Grandma, am I going to always be a wheelchair boy? Well, if that doesn't get your heart, nothing does. You know, (inaudible) Justin, walking isn't the most important thing in the world. You

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have something to give the world and you're going to...you know, you're going to be just fine. But when he asks you, Grandma, where am I going to go? What am I going to do? And there's no transportation for him to go to college. I believe before they used to pay for college, but now with the Disabilities Act that was taken away. This is what my daughter-in-law told me. I'm not sure if that's valid, but I think it is. It's been a huge financial strain on my son and daughter-in-law. They both are hard workers. Everybody pitches in. You know, both...all the other...the other two grandsons are just very, you know, very good in school sports and excel. They all just kind would do the best, you know, that we possibly can, but we still have this void for Justin. And physical therapy was there for him, although the insurance only covers so much of it. Shriners was there for him. I can't tell you...and we know we're fortunate. He can't walk and he can't do fine motor things. We're very fortunate because there's so many other more severe disabilities than Justin's, even though he's very, very handicapped. You know, whether it be his eye glasses or an insert for his wheelchair that's \$1,000, you know, I've kind of had to be there. They don't have the money. The insurance doesn't cover all this. The funds aren't there. And again, Justin is kind of...he's in the gap and his friends are driving. They're off to college. He wants to go to college. Finally, Munroe-Meyer now will provide transportation one day to Metro Tech. He is so excited, because these other funds have not been there for him. Munroe-Meyer has been wonderful. I contribute there. The family contributes there. But for his summer camp, I believe it's \$350 a week in the summer. How many families...you know, I think Justin goes two or three weeks in the summer, but that's a lot of money to a family with three teenagers and, you know, two that will be soon going off to college. I don't know how much more my...I just don't know how much more my son and daughter-in-law, you know, I just don't know how much more they, you know, they can endure. He just had surgery for a hiatal hernia. It set him back four months. And then he didn't have his physical therapy during that period so now we've got to maintain and try to get that recovered. But my ray of hope for Justin and these other young disabled adults like him is if there will be a Village of Promise, or a facility where these...they can have their peers. They maybe might work there. Maybe they'll work somewhere else. But most...some of them are employable.

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They tell Justin he's unemployable. I know he could be. He's very personable. He could be a dispatcher. He could be a greeter. And I know other...15 other friends of his that have a potential of being employed but they're kind of in the gap too. So I'm just here on his behalf and all of his friends that I have met through the years, as I've been there for him. I'm going to be there for him. He can't wait till I retire because I'm hoping I can find a business that, if that's what I have to do when I retire, is be there for him. So I do hope this funding, whether it's the Village of Promise or another facility, or whether it's for transportation, or schooling, or special therapy, these young adults are lost and they need us and they need us now. And I'm sure the list goes on. []

SENATOR LATHROP: Thank you. Senator Stuthman looks like he has a question for you. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Jeanne, first of all, I want to thank you for your testimony and I want to thank all of those that have come here. We really appreciate the fact, you know, of hearing from people that are in a situation and are looking for something to help. I just...it's more of a comment. I think the best gift for you, as a grandmother, would be that your grandson could find an employment and a social environment for him to be in. []

JEANNE PATRICK: I know. He wants to live independently though. He would like to, you know, he's got two or three friends that probably he could do that with, but they still have to have someone to assist them wherever they would reside. And they don't have the funds to provide that, you know? []

SENATOR STUTHMAN: And all you're asking is just a little bit of a help so that he could accomplish that. []

JEANNE PATRICK: I think the funding is obvious for all these needs, for all of these needs. []

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SENATOR STUTHMAN: So thank you very much for your testimony. []

JEANNE PATRICK: Thank you. []

SENATOR LATHROP: Thank you. []

LARRY CARTER: Good afternoon, senators. My name is Larry Carter. I've lived in Omaha for 15 years now. I have a 20-year-old son Jeff with...diagnosed at birth with mild cerebral palsy and significant cognitive disabilities. I'm actually one of the lucky ones. He has virtually no health/physical issues, other than a seizure disorder which is pretty much under control with medication. Mentally, he functions at probably about a second or third grader. He's never going to hold a competitive job, but he is certainly capable of doing things other than sitting in a workshop and putting things in bags and different things like that. He has a wonderful personality. He has no behavioral issues to speak of at all. He's very easily redirected, smiles, talks all the time, matter of fact talks too much (laugh) at times. I've been his primary caregiver. I retired. Fortunately, financially I was in a position where I was able to retire when he was 16 and my wife and I thought, as a male, that he needed my presence more as a caregiver. My wife has continued to work. It's a sustainable situation for the foreseeable future. But when I look at my son Jeff, he deserves the same ability and opportunity that any other citizen of the state of Nebraska does. He wants to live on his own, but he needs some assistance. He doesn't need 24-hour care, but he needs somebody to check up on him. He needs to be in an environment where he's with his peers. That's how he's going to develop. If you would have seen him when he went into school and what he's come out, it's just been a world of difference. I will echo a couple of comments that some other speakers have said. The Millard...we've been in the Millard school system basically since I think he was in third grade when we moved here. He has developed from both a maturity, an intellectual, although understanding that he's severely limited in that, communication skills, and if I can't find an avenue to get him into an environment with his peers, he's

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never going to...he's not going to develop any more, as good a relationship as he and I have, that's not fair to him that he's going to be living with me and my...and that. Because he's in an environment, he almost becomes in a cocoon when he lives there because he doesn't have his peers and we have limit...you know, we interact. What he and I...we're able to interact. We love to watch football together, we watch sports, but there's just...there's a limitation on what a 56-year-old male and his mother, how they can interact with a 21-year-old male. So it's imperative that for people like my...and, as I said, I'm the lucky one of a lot of these parents because I don't have to deal with some of the severe physical, behavioral and mental issues that come along and it is still a challenge and a very difficult thing to deal with. And I just urge you, these people, they deserve the opportunity that everybody else does. Thank you. []

SENATOR LATHROP: Thank you. Any questions? I don't see any. Thanks for coming down. I very much appreciate your testimony. []

RICH SECOR: I'm Rich Secor again. Just want to talk to you a little bit about my son for a minute or two. He doesn't talk. He has to be reminded to go to the bathroom. He overstuffs when he eats. He needs assistance to dress, wash his face, bathe, brush his teeth. He cannot cross the street without supervision. He cannot be left alone. He runs into things because he's awkward and because he has an abnormal separation of a C-1 and C-2 vertebrae in his neck. Consequently, he looks down when he walks and runs. He has the same intellectual capacity as a three-year-old. He has Down's syndrome. He picks at himself, making his fingernails and toenails bleed. He's very compulsive. He makes only superficial eye contact when he's spoken to. He will read a phone book and his way of reading a phone book is to flip every page, page after page, after page, minute, hour after hour. He's compulsive. He's also autistic. So my son has a dual diagnosis of Down's syndrome and he's also autistic. He's 15 years old. My wife and I just placed him on the waiting list in July, anticipation that when he's 21 we're hopeful that he'll be able to get services and there will be funding available. I just want to echo what Larry said and others have said up here. It's a...this is all about not Village of

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Promise. It's all about our concern about the availability of funds to serve the needs for adults with cognitive disabilities. And I think I want to stress, too, this isn't all about parents or caregivers having respite in the long term. It's all about enabling these individuals to maximize their potential. These individuals want to live away from home and they want to have these services, and it's important to recognize it's all about them. It's not about us as caregivers. Thank you very much and I appreciate the opportunity to make this testimony. []

SENATOR LATHROP: Thanks, Rich. I think Senator Wallman has a question for you. []

SENATOR WALLMAN: Yeah, thanks for coming, Robert (sic). As you looked at this list, I'm sure you did, how many is on there and all this, do you have a preference? Would it be community-based or an institution like BSDC where your son could go to or...? []

RICH SECOR: Well, I mean I have...I have a preference that he would end up in a village like a community like what we're planning which would have separate residential homes, would have caregivers living in the homes to watch after him. That there would be employment on that campus, such as maybe dog grooming, maybe there will be a retail shop, that kind of thing. There would be education opportunities for him to advance his education. There would be recreation opportunities, maybe a gymnasium, that kind of thing. []

SENATOR WALLMAN: Northwest Villages has a lot of this stuff, as you realize, in Iowa, but you can...if you have so much ability then you graduate out of there. You know what I mean? They will not literally take you forever. []

RICH SECOR: Right. Yeah, I think, yeah, I think that's a great point, Senator Wallman, that you make that I think any of these planned communities, whether it's group homes or a village concept, I think the idea is to try to maximize the independence of these individuals. And if they could eventually live on their own, I think you're right, I think they,

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quote, graduate and let's get them mainstreamed. []

SENATOR WALLMAN: Well, thank you for coming. []

RICH SECOR: Thank you. []

SENATOR LATHROP: Thanks, Rich. []

JASON TONJES: Senators and Chairman Lathrop, my name is Jason Tonjes, that's T-o-n-j-e-s. I came here today, I have a three-year-old daughter with Down's syndrome. I became aware of this issue probably sooner than most. I have known Rich for quite awhile and several months after she was born he asked me to come and join and listen to the few at the Village of Promise committee meetings. And through that, I, you know, learned that there's a problem out here. You know, I don't have a lifetime of stories and experiences like many of these people do, but I also don't want...don't really want to go through that for the next 20-25 years. I don't want to be back up here when my daughter is 25 having the same meeting. You know, it's something, I guess for my own benefit, my daughter's benefit and our ability to plan for her future, it would be nice to see something start happening within the state within the next few years. I do...you know, she just started with the Omaha Public School system this year. From what I've seen so far, the support there is tremendous. She's advanced considerably in her two months through the preschool. But I, you know, I continue to hear the stories of what happens after they're 21, and that concerns my wife and I. You know, I want her to have a place where she can live, she can be independent, do the things that the other kids do. I look at it now and they're a kid and they're happy and everything is carefree, and I'd like to see her be able to enjoy that when she hits her adult years. So I guess what I've really learned in the last few years, and I really encourage the state to do it, is, you know, to look at some alternatives. I mean, the village concept, which I do like, that might not be the alternative. We need to look at some cost-effective alternatives. We need to handle the staffing issues. I heard the gentleman from the Teamsters earlier today talking about

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the staffing issues. I actually have some experience as a...I'm a CPA by profession and I've done some auditing of one of the state's larger providers of these services and, you know, I always...I was told, you know, that they could potentially take on more people but the problem would be finding, you know, or affording people to care for them. At some of the rates that the individuals were being paid, the turnover was just too great and it became a difficult burden on the executive director and some of the key managers. So I don't have a lot to say, I don't have a lot of experiences. You know, I am concerned for the future. I really just want the state to maybe look for other alternatives and hopefully cost-effective ones. Thank you. []

SENATOR LATHROP: Very good. Thanks, Jason. I appreciate your testimony today. []

HAL LANKFORD: I'm Hal Lankford. My wife Elizabeth and I live in Omaha. We have a 49-year-old son with Williams syndrome who resides on the Mosaic campus in Beatrice. We've been so fortunate, I almost guilty...feel guilty sitting here. When he...we put him on a waiting list in Omaha when he was 18 with ENCOR. When he turned 21, of course, the program, there was nothing available, so we went to the cupboard and they had lost the list. So someone told us about the Martin Luther Home in Beatrice and we were so lucky to get him in there. It is a fantastic place. And the way this testimony ties into the waiting list is that I'm afraid that underfunding of that institution is going to lead to a longer waiting list. But I'll get to that in just a second. We, you know, it's a long ways from Omaha down to Beatrice, when you go down there every ten days or two weeks or something, and we're obviously aging so we wanted to find a place closer to Omaha or closer to our kids, Milwaukee and Chicago. So we looked at places in Wisconsin, Illinois, Iowa. We always come back to Martin Luther Home, now Mosaic. It's the best place that we have found for him. I think that apparently the folks in Health and Human Services don't eat or they don't drive cars. Their proposed budget raise for the ICF/MR down there is 1 percent. That's really going backwards. And they won't permit a salary competitive. It's, I think, \$8 and something. They allow \$10 and something for BSDC, and it's hard enough to find somebody at \$10 an hour. When you're behind the curve

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with \$8, they...last month they had 18 vacancies. So I don't know, these people aren't necessarily obligated to provide this service to the state of Nebraska. We're fortunate they do. We'd have a heck of a lock bigger problem if we didn't have Mosaic providing these services. And I want to add my statement that we really appreciate your dedication and I have heard that you don't even get time and a half for this work.
(Laughter) []

SENATOR LATHROP: That is true. (Laughter) I'll see if there's any questions. I don't see any but we...oh, I'm sorry, Senator Wallman does have a question for you. []

SENATOR WALLMAN: Thank you for coming. Mosaic is in my district, as you well know. []

HAL LANKFORD: Yes, it is. []

SENATOR WALLMAN: And I agree with you, we have to find better funding for employees there. And I'm glad you're happy with them, but I do know they have a quality control person, goes around to different states. I know that individual and she checks up on the institutions and much tighter control probably than we have in our own state. So thank you. []

SENATOR LATHROP: Thank you very much. We appreciate your testimony today. []

HAL LANKFORD: Thank you. []

SENATOR LATHROP: Are there any...yes. How many other people are interested in testifying today? Okay, one, two other hands. Good. []

GAYLE WIDICKER: Hello, my name is Gayle Widicker, G-a-y-l-e W-i-d-i-c-k-e-r. I just was here today to listen. I was originally from Nebraska. I graduated from UNL with a

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special ed degree in 1974. I married, moved to North Dakota. Now, because of a divorce, I have returned to Lincoln. I brought my special needs daughter with me. She is 24 years old. I am shocked and surprised at what I ran into when I returned with her. When I applied for DD services and was told there would be five years, ten years at most for her to get day services. I was told I'll never see residential services because she's got a mommy that loves her. So what I have been...what I've been up against is all the parents telling me, Gayle, have you bought your house yet in Lincoln? I said, no. Then don't. Leave the state. It's been recommended I go to Iowa, I return to North Dakota. It surprises very many people that North Dakota is on the cutting edge. When I left Lincoln with school, we were on the cutting edge. For me to return to Nebraska and see where the state is at on this is heartbreaking and it's heartbreaking that my state of Nebraska, my home state, people are telling me to move away. This is what I am faced with right now. When I returned here, I had BlueCross BlueShield of North Dakota. BlueCross BlueShield of Nebraska denied me, so I need to find employment. My daughter was diagnosed with a brain lesion. Because of this, she has some cognitive disability, minor motor disability, but a severe seizure disorder that is noncontrolled by medication. She pretty much needs 24/7, some type of care because of the seizures. On Tuesday, she went through ten grand mal seizures. This is on the medication that is state of the art that I've been through everywhere. So right now I've been in Lincoln now for 11 months. I have 24/7 care of my daughter and am unable to find a job to cover my insurance. Now Lindsey (phonetic) went through the transition program at the schools in North Dakota. She did very well. Once I came down here and found out we were not going to get services to maintain her skills that she did have, we volunteered at the Tabitha Nursing Home two to three times a week. She would...there's a lot of things she could do, but she does, because of the seizure disorder, she has simple complex, complex partial, and atonic clonic seizures. So she would need job-supported services and she would need transportation of some kind. Even putting her on a bus would be very risky. Right now the divorce is...we are in the middle of the divorce and it looks like I'm going to be forced to return to North Dakota, where all my family is in Nebraska, his family is in North Dakota. But so we are forced to leave, and I think you need to know

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that. Your parents are telling new parents to leave the state because of the situation of your developmental disabilities in Nebraska. I think that's very sad and I think it's very poor advertising for your state, our state, it's mine. I mean, I'm back here and I had intended to buy a home, live here and my retirement here. I guess that's all I have to say. []

SENATOR LATHROP: Thank you very much for that testimony. Senator Stuthman has a question for you. []

GAYLE WIDICKER: Yes. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Gayle, what type of service were you getting in North Dakota then... []

GAYLE WIDICKER: Okay. At the... []

SENATOR STUTHMAN: ...or give me the difference between what you were getting there and what you can't get here. []

GAYLE WIDICKER: Okay. I will clarify this. We were on a farm and, after graduating at 21, she was not ready to go into services. And then, you know, they're talking about catastrophic things happening, whether or not they die or they become ill. They are not figuring in the factor of a divorce that puts you in another different situation. Because my son and my husband and I were taking care of her predominantly on the farm. She was just getting ready to go into services when this happened. In North Dakota, she would have an apartment with supported work services. She would have a direct service provider that would take her to work, be on the job with her, return her to the apartment. The apartment has, oh, she would probably be mostly alone in the apartment, but there would be a two-way, I don't know, intercom system so that the provider of the apartment, the person that's always on duty within the apartment, would know if she had

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a seizure and could assist her. There would be assistance in fixing food, cleaning, anything, depending on the amount of assistance she would require. []

SENATOR STUTHMAN: And she could have...could have received those services, you know, almost immediately after she... []

GAYLE WIDICKER: Immediately. []

SENATOR STUTHMAN: ...graduated out of school. []

GAYLE WIDICKER: Immediately, yes. []

SENATOR STUTHMAN: There was no waiting period there or anything. []

GAYLE WIDICKER: No waiting list. When I talked to North Dakota, they were shocked you were still using a wait...that you had a waiting list in Nebraska. They did not think...they were just shocked. They were very sorry to hear that. I have looked into Iowa, because I've been told your family is all in Nebraska, go across the river. Iowa does not have...there are only a few counties that have...I think there were four counties maybe that had a waiting list. []

SENATOR STUTHMAN: And before you came back did you realize there was a waiting list here? []

GAYLE WIDICKER: No, I did not. When I left Nebraska I... []

SENATOR STUTHMAN: I mean when you left North Dakota. []

GAYLE WIDICKER: No, I did not. I would have never dreamed that North Dakota was in...the state was in this predicament because of the way it was when I left. You were

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cutting edge when I left. I expected it to be the same. That was my mistake. I had a lot of faith. In fact, many of my friends were so tickled that I was coming back here, that there would be better facilities for Lindsey (phonetic) down here, because they were bigger, they would have more opportunities, more people with her...that function on her level. Because North Dakota is very rural and we were in rural North Dakota, and so everybody was, you know...but the facilities were wonderful. []

SENATOR STUTHMAN: Yeah. Well,... []

GAYLE WIDICKER: But...and I do want to...I've had people say, well, Gayle, that's nice that you want to return here, but, you know, you've paid all your taxes in North Dakota. We own property in Lincoln. We have paid income tax in Nebraska for 30 years. We have paid property taxes in Lincoln for 30 years. I am not one of these that's just looking around for the best place, for the best services, which state do I go to, but I've been told not to come to Nebraska and I find that highly embarrassing. []

SENATOR STUTHMAN: Well, thank you, Gayle. Thank you for your testimony. []

SENATOR LATHROP: Think that's it. Thank you very much for coming down today. We appreciate it. []

KATHY HOELL: Good afternoon. My name is Kathy Hoell, H-o-e-l-l, and actually when I came today I was not going to testify, but I decided this is probably one of the best chances I'm going to get to say what I need to say. One, I am on the LR156 board group. We have looked at this waiting list repeatedly over the years. There have been recommendations already made for this waiting list that we have never implemented. Mary Gordon's group contracted with Senator Byars and Deb Weston of the Arc and they did a study with recommendations for addressing the waiting list. This was a couple of years ago. It was never implemented. And I'm going to tell you exactly what I told the group (inaudible) waiting list. The disability...I know your charge is only

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developmental disability, but the fact of the matter is the disability system in Nebraska is broken and just fixing pieces and parts is not going to make (inaudible). We have the DD waiting list. They've changed the name in Behavioral Health. (Inaudible) he's changed the list to not a waiting list. We have people with disabilities who are not getting the services they need. One of the parents talked about employment. One of the key pieces of legislation that we have been trying to push through the Medicaid Reform Council is the Medicaid buy-in which would allow people with disabilities to go to work and to still have...still keep the supports and services they need because the fact of the matter is most private insurances aren't going to cover them because of preexisting conditions. Another problem with our system, we have...whether it's transportation, respite or whatever it is, you have to use these approved providers. You're paying \$25 for a one-way trip. But guess what. What other states do is you can get a person, whether it's a neighbor or a nonresponsible family member, to provide the same transportation or respite service for like \$10 bucks an hour. It's cheaper. It's more cost-effective. The state of Nebraska is paying so much for the management at HHS that we are cutting back on disability services across the state, whether it's in Columbus, whether it's in Omaha. No matter where it is, we're doing a really big disservice to these people. People with disabilities have the same hopes and dreams as anybody else and we're just not letting it happen. The best thing the state could do is to basically trash the entire disabilities system, the silos, (inaudible) chances divide into and create a unitary, one single disabilities system, whether you have a developmental disability, whether you have a behavioral health disability, or if you have a physical disability. The choice is yours. You have one place to go to, one place to get services, no waiting list of disability. Everybody that's on the waiting list has already been deemed eligible. We need to provide them with an entitlement that if you are declared disabled by whatever system they choose, you get services. We don't put people on (inaudible). Waiting lists are archaic, barbaric. We've got people out there who are 76 years old trying to figure out how, if they have a heart attack tomorrow, what is going to happen to their son or daughter. That is not fair to them and it's not fair to the person with a disability. I'm just getting over laryngitis too. (Laugh) Our system is just...I have lived

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(inaudible) United States and I have been involved with disability for 25 years on a national level, and I have never seen anything as convoluted as I have in Nebraska. This is (inaudible) just does not make sense. Now all the Village of Promise, I see that probably as just another form of an institution, but I'm not even going to go there, whether I agree with it or not, because I understand where these people are coming from. They want some place where their children can get the supports and services they need, and if it means building a Village of Promise or whatever, that's the only way they can do it. Maybe that's what has to happen. But I think the Legislature has a responsibility to its most vulnerable citizens and step up to the plate and provide them with the services and supports that they need. Thank you. []

SENATOR LATHROP: Thank you, Kathy. We appreciate your testimony, your monitoring this commission, and your appearance once again. I don't think we have any questions for you, so thank you again. I think there was a hand or two that was left. Yeah, come on up. []

TAMMY WESTFALL: I promise to be brief. []

SENATOR LATHROP: You're fine. You're fine. []

TAMMY WESTFALL: (Exhibit 2) Senator Lathrop and members of the committee, my name is Tammy Westfall and I gave brief testimony last month and I just want to do a quick follow-up in regards to the testimony that I gave last month. I am the regional vice president for Nebraska services. The Lankfords were up here earlier and had told you about the budget, the biennium budget that has requested 1 percent increase of funding, and I just wanted to reiterate that that basically means for our three ICFs approximately \$200,000. Eighty percent of that...or \$80,000 of that would be the cost to the state. The 60 percent, other 60 percent, would be the cost to the federal government. So that's \$80,000 (laugh) for the biennium that has been requested for three ICF facilities for 245 people. So I just kind of wanted to put that out there in

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perspective. So as far as wage increases, increasing starting wage, you know, benefits, that's just not going to cover it. The only other thing I want to say today is that I wanted to let you know that back in July 8 Mosaic submitted a proposal to HHS to operate some small ICF facilities throughout where Mosaic currently provides services. We submitted a complete proposal and this would be to assist in the transitioning of BSDC, folks from our own ICF facilities into the community, nursing homes. But I just wanted to let you know that. We currently operate several small ICF settings in other Mosaic states where we operate, and that's in Texas, Indiana, and Iowa, and then, as you well know, we have the small nine-bed facility in Grand Island. Just want to say, in ending, is that we again are willing to partner with the state in assisting in any way that we can and that's really all I have to say today. []

SENATOR LATHROP: I think you're going to get some questions... []

TAMMY WESTFALL: Okay. []

SENATOR LATHROP: ...and beginning with Senator Wallman. []

TAMMY WESTFALL: Okay. []

SENATOR WALLMAN: Yeah, thanks for being here, Julie (sic). I'm going to ask you just a point, but I'm pretty blunt. Do you think Mosaic could run that institution better than it's being run? []

TAMMY WESTFALL: I would not...I would not comment on that. I do feel that Mosaic provides good services... []

SENATOR WALLMAN: Oh, I do too. []

TAMMY WESTFALL: ...but I just...I wouldn't comment on that. []

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SENATOR WALLMAN: Okay. []

SENATOR LATHROP: No other questions. Thank you very much for your testimony. []

TAMMY WESTFALL: All right. Thank you. []

ALAN ZAVODNY: (Exhibit 3) I was going to have to get mad at Tammy if she made you mad right before I came up. Senator Lathrop, members of the committee, my name is Alan Zavodny, A-l-a-n Z-a-v-o-d-n-y, and I'm the chief executive officer of NorthStar Services and current president of the Nebraska Association of Service Providers, and recommending other community-based providers. And we didn't want to let the waiting list testimony go by today without offering the issues that we feel will help you as you prepare your final report, that what the providers would need to make this work. And our three priorities are, to make this viable: reimbursement rates at reasonable amounts to cover costs; a person-centered funding system based on need, not available resources, at any given point of time; and finally, flexibility in funding, not constrained to a month-to-month reconciliation, a small emergency fund that covers special circumstances as they arise and people's needs change, and approve a funding level and not just adjust it down in six months, and we'd like to see funding based on outcomes as opposed to habilitation that we talked about earlier. It is our hope that you will see fit to include in your final report that community-based salaries should be funded at 100 percent of a Tech II salary. It would be helpful to set that amount about 10 percent above the starting wage for the Tech II to give us the ability to give raises, but we'd be happy with getting to the Tech II level at this point. And that's all I have. []

SENATOR LATHROP: Alan, right now are the folks that provide services in the community-based settings, their pay is tied to what we're paying a tech down at Beatrice? []

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ALAN ZAVODNY: The Tech I, which they don't hire at, and it's 90 percent of that. []

SENATOR LATHROP: So it's 90 percent of the lowest level... []

ALAN ZAVODNY: That exists. []

SENATOR LATHROP: ...of a care provider, direct care provider, at Beatrice? []

ALAN ZAVODNY: That is correct. []

SENATOR LATHROP: And so what's that right now? []

ALAN ZAVODNY: Oh, that's a good question. I'd hate to guess but last time I remember checking it was around \$9.38, but don't hold me to that. I will get that... []

SENATOR LATHROP: Is the \$9.38 what they're paying for somebody in Beatrice, or is that 90 percent of it or what you're funded at? []

ALAN ZAVODNY: We...\$9.38 was the Tech I starting. it was right around there last time I checked, and we get 90 percent of that. []

SENATOR LATHROP: So you're under. You're \$8-something an hour? []

ALAN ZAVODNY: Yeah, our starting wage in NorthStar is right around \$9 an hour. We are actually paying more than we're funded for, but we take it from operating. Because it would scare you the quality of people you get for under \$9 an hour. It scares me. []

SENATOR LATHROP: Yeah. They're not...yeah, okay. []

ALAN ZAVODNY: Keeps me awake at night sometimes. []

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SENATOR LATHROP: Are you mostly up in northeast Nebraska? Do I remember that?
[]

ALAN ZAVODNY: Twenty-two counties in northeast Nebraska. []

SENATOR LATHROP: Okay. I think that's all I had. I don't see any other questions. []

ALAN ZAVODNY: Thanks. []

SENATOR LATHROP: So thanks again for coming back. []

ALAN ZAVODNY: Uh-huh. []

PATRICK BOND: Thank you, Senator Lathrop and senators. I'm not...my name is Patrick Bond, B-o-n-d. I'm not part of any committee, any special group. I'm actually a parent of an angel and my angel's name is Christian (phonetic) Bond. He was diagnosed with a condition called periventricular cystic inflamatia (phonetic), and basically it can be misdiagnosed as autism, but he can grow out of it with the right promptings, unlike autism. The reason I come to you today, and I came at the request of the president of the Madonna School in Omaha, Sister Michelle Faltus, to be a support. But as I sat here, I became evident I have to make known what we go through, and my son is only eight years old. When he was diagnosed, we were told he'd be put on the waiting list. When I contacted about the waiting list what I was told was don't put yourself on the waiting list, it's not going to happen. When he went into OPS, I was told the same thing--don't do on the waiting list, it's...nothing is going to happen, it's too big. When we pulled him out of OPS because OPS wasn't providing what he needed and personally funding his education at Madonna School...and you'll have to bear with me. I'm not a public speaker so I'm kind of shaking. []

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SENATOR LATHROP: You're doing fine. You're doing fine. []

PATRICK BOND: When we did that what I was informed by many people was, as another person had said, get out of Omaha, get out of Nebraska, and my response was, well, we've got him in Madonna, he is doing so well. They said, that's fine, Madonna has a wonderful program that will get these students to a point when they graduate, but there's nothing afterwards; you'll be on a waiting list, leave the state. And it scares me because I have an eight-year-old who dreams of having a job, and it's not a job in computers. His dream is to be a Wal-Mart greeter. He's not going to be able to get that because there's not going to be that kind of support. If you look at my son, he looks like any other child. You watch him run; you know there's a problem. He's a very loving child. He's a very deep-feeling child. And it scares me to see the waiting list as it is. And when I went last week to actually sign him up on it, I was told you're looking at 15 to 20 years past when he turned 21. And I at that point said, well, we will figure different aspects. But to look at what's going on and to see my son with the idea of just being a greeter but not being...and knowing that there's not going to be that kind of support at that time, I mean, I'm not a very wealthy individual at all. I drive a truck for a living. But when it comes down to these people, you need to ask yourself, when you graduated high school, when you turned 21, each one of you decided which road you were going to take and you had the ability or was given the ability to make that happen. My son, at age eight, has an idea of the road he wants to take but has not the ability and, as the way the law stands right now, has not the support to make that happen. Thank you. []

SENATOR LATHROP: Thank you very much, Mr. Bond. That was well put. I don't see that we have any questions, but we do appreciate your testimony today. []

PATRICK BOND: Thank you for your time. []

SENATOR LATHROP: Yep, you can place it in the box and make yourself comfortable.
[]

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ELIZABETH LANKFORD: I didn't intend to talk but you can't really keep me quiet. I'm the other half of the couple that have a son in the Mosaic campus in Beatrice, and I just wanted to say that... []

SENATOR LATHROP: Ma'am, can we have you give us your name so we can make a record out of... []

ELIZABETH LANKFORD: Oh! Elizabeth. Elizabeth Lankford. []

SENATOR LATHROP: Okay. Great. []

ELIZABETH LANKFORD: Okay. And I just wanted to say that the kind of people they have down there, the staff that they have, are so dedicated and we...they're not going to live forever and we want to keep staff there that are as dedicated as they are, and they do need more dollars. And anyhow, the type of thing, I brought this--my husband says, oh, you shouldn't do that, but I did. This is our son. He was diagnosed as severely to moderately mentally retarded after he was a few months old and he has Williams syndrome, so he has a gift of music and he's able to play by ear. He just taught himself and plays for them. And this is a staff member that, during their chapel service, sits with...sat with him and would ask him to play certain things with him and he would play along. They take extra care. They do extra things. And that's why I think the Village of Promise here in Omaha is going to be the same type of place. I really hope they get this off the ground because it does have a lot of promise. Thank you. []

SENATOR LATHROP: Thank you. Dan, are you getting out of your chair? []

DAN MALONE: Just for a second. Senator Lathrop and committee members, my name is Dan Malone and I just want to share a quick thought with you. I relocated back to Nebraska some time ago and I have a special needs son who will always have to have

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an infrastructure around him. There's no question about that. I read in the paper one day where the...a senator here at the Legislature had introduced a bill, and it passed overwhelmingly, to provide a \$6.5 million grant to real estate developers that could provide housing for disabled citizens of Nebraska. Sounded like a noble plan to me and, being new to Nebraska, I called up here to Lincoln and asked for that senator's office and asked his secretary to send me a copy of the bill and any comments from the committee and whatever I could learn about it, and it didn't come. And so I waited a week or so and called again, and again it didn't come. And so, being genetically challenged and Irish, I called and asked for the senator himself and I was...got his assistant and I explained my search here and she said, well, Mr. Malone, I should tell you, yes, the body approved that voice vote but, if you'll notice, it's for a fiscal year two years from now, and next year it will be pushed off again and by the time it comes up it will be gone; it's not going to happen. I thought, wow, that's an interesting discussion. And I wanted you to know that discussion was 20 years ago. My son is now where he's looking for housing. He also needs to get on the waiting list. I'm kind of a right brain thinker. If you take the people that got off the list and divided it into the number of people on the list, I'll know why I'm on the list, okay? So I just want you to know there's a lot of voiceless people out there. I appreciate you listening to these discussions today. The housing is the big deal. And before I shuffle off this world I'd like to make certain that he's not a candidate to fall through the cracks. And I'm going to leave you with this last chilling thought. It's chilling to me, as a dad. He's a big boy, got hearing disabilities, can't hear anything, got eight brothers and sisters. If somebody would push him or he thinks they're making fun of him do I think he'd smack them? Yeah, I do. He hasn't, but I...and he goes to Madonna School too. He's a good kid but if in another environment, three years from today, four years from today, could he do that? I asked a social worker who's familiar with these people--what happens to him if I'm not here and he hits somebody? And he's nonverbal, can't speak. Oh, he'll be up at Immanuel Hospital, he'll be in a locked unit; they'll have more drugs in this kid than you can imagine, and if he's not responsive and they can't find a cure plan and they can't find a housing environment, he goes to Beatrice State Home. Now that's almost a chilling end to a bad

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mystery movie for a dad, and I just want you guys to think about that as you drive home today, that these are kids that are sitting around, waiting for some response, and I hope that doesn't take another 20 years. []

SENATOR LATHROP: Thanks, Dan. Wait a minute. We got some questions. []

DAN MALONE: Yes. []

SENATOR STUTHMAN: Dan, I have one comment. []

DAN MALONE: Sure. []

SENATOR STUTHMAN: When you was talking about, you know, that bill that was introduced and stuff like that... []

DAN MALONE: Yes. []

SENATOR STUTHMAN: ...and as the senior member of the legislative body, the group that is here, I thought, my gosh, I didn't know that that had happened, but I've only been here six years. []

DAN MALONE: Well, yeah. []

SENATOR STUTHMAN: So...but I'm glad you cleared that up. I was... []

DAN MALONE: It was 20 years ago. []

SENATOR STUTHMAN: Yeah. So thank you very much for clearing that up. []

DAN MALONE: Yeah. Thank you. []

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SENATOR LATHROP: Thanks, Dan. []

DAN MALONE: You bet. Thank you. []

SENATOR LATHROP: Is there anyone else interested in testifying today? Okay, that will conclude our hearing for today. We will reconvene tomorrow at 1:30 for additional hearing. Thank you. []

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[]

The Developmental Disabilities Special Investigative Committee met at 1:30 p.m. on Friday, October 17, 2008, in Room 1524 of the State Capitol, Lincoln, Nebraska. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Tim Gay; Arnie Stuthman; and Norm Wallman. Senators absent: Abbie Cornett.

[]

SENATOR LATHROP: Good afternoon, everyone. My name is Steve Lathrop. I'm the State Senator from District 12 up in Omaha, Ralston, Millard, those areas. And we're here today to continue the hearings on our commission, the LR283 commission. Today we are going to have our last hearing. So this is kind of the last opportunity to speak and to be heard. We have scheduled speakers today. We've asked Ron Stegemann, who is the CEO at Beatrice, to speak first. We'll have questions for Ron and want to talk to Ron. And then John Wyvill is the director of Developmental Disability Services, and Chris Peterson, who's the CEO of Health and Human Services, to kind of round out our investigation and our study. The usual rules will prevail. I see most people here are faces that I recognize. We're glad you're back and that you continue to be interested in the subject. Please make sure your cell phones are turned off or at least to vibrate so we're not interrupted by those calls. Senator Wallman, get to that phone. (Laughter) And then we have three people that are going to speak. If you have anything to add, this being our last hearing, if you had anything to add that's new and you care to come up we'll take a little bit of time at the end for some brief comments, if you have any. I'll also take a minute to introduce my colleagues. To my far left is Senator Wallman from down around Beatrice, what's the name of that town...? []

SENATOR WALLMAN: Cortland. []

SENATOR LATHROP: ...Cortland, okay, from Cortland; Greg Adams from York; Tim Gay from Papillion; Doug Koebernick is my assistant; and then John Harms from

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Scottsbluff; and Arnie Stuthman from Platte Center; and our clerk today is Beth Otto who does a great job of keeping a record. And Beth always gives me...(laugh)...she always gives me something to read, and I never read it. But it's so sweet that she does that. (Laughter) Mostly, she wants to make sure that the phones are turned off, so she's kind of the person that's trying to make sure that we get good audio. Speak up into the mike. And then if you're going to testify today, please fill out a sheet, put it in the box when you come up so Beth has the correct spelling of everyone's name. With that, I think we'll start with Ron. []

RON STEGEMANN: Good afternoon, committee members. My name is Ron Stegemann, S-t-e-g-e-m-a-n-n. I am the chief executive officer at the Beatrice State Developmental Center. I'm here to answer any questions you have for me today. []

SENATOR LATHROP: Good. Do you have anything you want to say before we start asking questions, Ron? []

RON STEGEMANN: No, just that I appreciate the opportunity to visit with the committee again and sharing information that I have that might help you in creating the recommendations, report that you have to deliver in December. []

SENATOR LATHROP: By December 15, yeah, you're right. []

RON STEGEMANN: Okay. []

SENATOR LATHROP: We're glad you're back. And for those of you who have not been here for every meeting, Ron was...testified in the first hearing where we kind of got our feet wet on the subject matter, and then testified in Beatrice when we took our hearing down there. And you're back today. CEO of the Beatrice Development Center, is that right? []

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RON STEGEMANN: Yes, sir. []

SENATOR LATHROP: Ron, how long have you been the CEO? []

RON STEGEMANN: I've been in the CEO position for just over a year now. I took over as acting CEO at BSDC, I believe, on October 17 of last year. []

SENATOR LATHROP: So how long were you acting CEO before you became the CEO? []

RON STEGEMANN: I started as acting CEO in October and, I believe, became...got the position permanently in December. []

SENATOR LATHROP: Of '07? []

RON STEGEMANN: '07, yes, sir. []

SENATOR LATHROP: Okay. Kind of came in the middle of the firestorm. []

RON STEGEMANN: Yes, sir, very much so. []

SENATOR LATHROP: Okay. What did you do for the Beatrice Development Center? You came from within. Tell us what you did before you became the CEO. []

RON STEGEMANN: I have been at BSDC a little over 19 years now. September was my 19-year anniversary. My responsibilities within the organization started as a human services treatment specialist. Their primary focus at the facility is to do assessments to determine where people are within their developmental disabilities to create learning programs. Based on what the team approves, each individual needs to learn and then to teach the developmental technicians or our direct care staff how to run those learning

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programs with each of the individuals, monitor those programs, monitor the running of those programs, and then make any revisions as necessary. HSTS is a member of the interdisciplinary team, and as such they have a lion's share of what we do in terms of habilitation for each of the folks. []

SENATOR LATHROP: Okay. So you were involved in direct care. []

RON STEGEMANN: I was not a direct care staff person. However, the HSTSs serve very much in the direct care role in a lot of instances. They may cover for breaks, lunches. They are involved with the presentation of active treatment as well as the monitoring of it as well. So very close to the direct care position, yes. []

SENATOR LATHROP: But that interdisciplinary team, that's the bringing together of the different talents, have them evaluate and look at each particular patient, develop plans, make sure the plans are being implemented. []

RON STEGEMANN: Yes, sir. I believe you may have received, in information today, what that interdisciplinary team looks like. []

SENATOR LATHROP: We did get a stack of documents... []

RON STEGEMANN: Okay. []

SENATOR LATHROP: ...just a few minutes ago. And I got to tell you, we couldn't get through them in the time we had. []

RON STEGEMANN: I understand. []

SENATOR LATHROP: So we'd have a hard time responding to what's...or knowing exactly what's in that stack of documents. []

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RON STEGEMANN: But you're correct, it is all those various disciplines at BSDC. And they do assessments as designated and they will create reports for recommendations of any learning or training or service programs the individual needs to be involved with. And then the team comes together, prioritizes what each individual be involved with over the upcoming year. And then the plans are created and set forth and implemented. []

SENATOR LATHROP: Okay. Ron, as you probably know, we have yesterday spent the morning with the folks from CMS. You've been involved in their surveys, at least you've made the place open and knew that surveys were being undertaken even before you became acting director or acting CEO. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And yesterday, and I want to try to give you my judgment or our judgment because I think I can speak for the commission, what we were...what was explained to us by CMS is that when they began, when they conducted a survey in 2006 they found BSDC to be out of compliance. And I acknowledge right at the beginning you were not the CEO when this happened. In September of '06 they found us to be out of compliance or not meeting the conditions of participation seven out of eight of them. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Which appeared to be some kind of a record for the number of conditions of participation not met by an institution. []

RON STEGEMANN: Along with the 431 pages of citations. []

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SENATOR LATHROP: Right. And yeah, the conditions of participation for the folks who don't understand, as we've been taught in the last several months, those are sort of the big picture, the big offenses that an institution can create that provides developmental disability services. Would you agree with that? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And those being out of the conditions of participation in seven out of eight categories means that there are a lot of smaller regulations that are being not met or violated in order to come up with that kind of a conclusion. Would you agree with that too? []

RON STEGEMANN: It can be a number of smaller violations or it can be what they determine to be a systemic issue. []

SENATOR LATHROP: Okay. Since that time, the state of Nebraska has had opportunities to provide plans for how we're going to rectify that and then follow-up surveys have been done. Is that right? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And from what was explained to us yesterday, and we got a little, kind of a cheat sheet from CMS that shows that they've done about eight follow-up investigations since then, all of which have still concluded that we've been out of...not met conditions of participation on every one of those occasions. []

RON STEGEMANN: I don't believe there's been that many follow-up surveys. There have been that many visits possibly due to them coming back for immediate jeopardy issues. []

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SENATOR LATHROP: Okay, you're right. They've been there for one reason or another on eight other occasions. And on each occasion they have concluded, and whether it's been a survey or a follow-up or in response to an immediate jeopardy, they have continued to find that we are not meeting the conditions of participation, most oftentimes, four or five out of the eight. []

RON STEGEMANN: When they come in on those occasions you're referring to, if it's for a follow-up for an immediate jeopardy, that is the only issue they look at when they come into the organization. They do not do a survey to look at conditions. They are only looking to alleviate the immediate jeopardy situation. []

SENATOR LATHROP: Okay. There...the document they gave us indicates that they had a column here for conditions of participation not met. And each of those occasions that they were here they had lists of conditions not met. []

RON STEGEMANN: I... []

SENATOR LATHROP: Can't comment on it. []

RON STEGEMANN: ...wasn't here yesterday. []

SENATOR LATHROP: Okay. []

RON STEGEMANN: I don't...I haven't seen the document you're referring to. []

SENATOR LATHROP: Okay. Okay. Well, the state's response to the conditions of participation not being met and the problems with our certification with CMS was to bring in Liberty Mutual or, not Liberty Mutual, (laugh) Liberty consultants. Is that right? []

RON STEGEMANN: At one point, yes. []

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SENATOR LATHROP: All right. And they were hired to come in for what purpose? []

RON STEGEMANN: To assist Beatrice State Developmental Center in meeting the conditions of participation. []

SENATOR LATHROP: Their contract, did you have anything to do with entering into that contract? []

RON STEGEMANN: No, sir. []

SENATOR LATHROP: All right. But they came... []

RON STEGEMANN: Well,... []

SENATOR LATHROP: Go ahead. []

RON STEGEMANN: I need to qualify that. That was discussed with me, but I did not, I was not a part of the contract itself. []

SENATOR LATHROP: Okay. Did Liberty come into the Beatrice Development Center for the purpose of looking at the operation and trying to bring us into compliance with the conditions of participation? []

RON STEGEMANN: They started a relationship with us in creating a plan of correction. And it grew into what you've referred to, which is looking at the organization and bringing us into the conditions. []

SENATOR LATHROP: I don't know how important this is but it was a contract worth over \$1 million. []

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RON STEGEMANN: Yes, sir. []

SENATOR LATHROP: Okay. So it wasn't just somebody that came in and looked at a small aspect. They were going to examine, in fact did examine the entire operation. Would that be true? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And they made recommendations on how to improve the entire operation with two goals in mind. One was so that we would meet the conditions of participation and not lose or certification to CMS. Goal number one? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And goal number two would be just to have the operation up and running in a way that would also satisfy the Department of Justice. []

RON STEGEMANN: At that point in time we had just, actually a year ago this month Department of Justice had just did their survey. So they would have not...we did not have... []

SENATOR LATHROP: They came in ahead of that. []

RON STEGEMANN: ...the report done. []

SENATOR LATHROP: Okay. Well, in any case then at least the second, the second purpose was to have them just make recommendations so the place ran better. []

RON STEGEMANN: Right. []

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SENATOR LATHROP: Okay. They issue a report which was done in April of this year. Is that right? []

RON STEGEMANN: That's when the majority of the Liberty staff left. So... []

SENATOR LATHROP: And on their way out the door didn't they leave behind a report. []

RON STEGEMANN: They sent a report after a period of time, I believe, to Director Wyvill. []

SENATOR LATHROP: To who? []

RON STEGEMANN: Director Wyvill. []

SENATOR LATHROP: Okay. To John Wyvill. []

RON STEGEMANN: Right. []

SENATOR LATHROP: Okay. And that kind of listed their recommendations on how...what Beatrice State Development Center needed to do in order to get into compliance and to run properly and meet the standard of care in the industry. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Okay. So Liberty leaves behind a list of things that they say: These are the things you need to do, in their report. []

RON STEGEMANN: Yes. []

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SENATOR LATHROP: They help reorganize, in some respects help to reorganize the Beatrice Development Center. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And kind of at the same time as all this is going on, we're getting things from CMS that they want to see done. []

RON STEGEMANN: Um-hum. []

SENATOR LATHROP: Is that true? []

RON STEGEMANN: Yes, sir. []

SENATOR LATHROP: Okay. And then the Department of Justice issues its report. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And that, we're all familiar with what that letter said and what their findings were. But ultimately, the state enters into an agreement with the Department of Justice, does it not? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And in that agreement the state of Nebraska and the federal government, the Department of Justice enter into an agreement. And the agreement, basically, sets out the things that the state will do in order to improve the Beatrice Development Center. []

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RON STEGEMANN: Correct. []

SENATOR LATHROP: And in that report or in that agreement it generally provides for when a variety of things needs to be done. []

RON STEGEMANN: There are dates within it, yes. []

SENATOR LATHROP: Right. And it starts out early on and says: These things will be done within 90 days, unless there is a more specific date provided for, doesn't that...? []

RON STEGEMANN: Correct. []

SENATOR LATHROP: Okay. And I'm not going to ask you about all of those things right now, Ron. But I do want to ask you generally, since the 90 days have gone by, there's probably 165 things in here, would you agree? []

RON STEGEMANN: I didn't count but you're probably accurate. []

SENATOR LATHROP: The paragraphs are numbered and each one of the paragraphs... []

RON STEGEMANN: Oh, okay. []

SENATOR LATHROP: ...kind of say, you will do this and we will do that. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Okay. Not all 165 need to be done within 90 days but a good number of them do. []

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RON STEGEMANN: Yes. []

SENATOR LATHROP: And they include things like reorganizing different parts of Beatrice or providing for staffing, securing the services of a neurologist or a psychologist, those kinds of things. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Now what I would like to do is to ask you with respect to the Department of Justice, the 90 days had passed. How many of those things do we actually have done? []

RON STEGEMANN: I couldn't tell you a number. I can tell you that the Department of Justice, Dr. McGee, who is the independent expert that's working with them, brought a team into BSDC and they spent approximately two and a half days at the facility with the purpose of checking to see where we are at in our implementation process. And... []

SENATOR LATHROP: When were they there, Ron? []

RON STEGEMANN: I would guess they were probably at the facility three weeks ago. []

SENATOR LATHROP: Okay. They're...and so that people understand, you and I both read this agreement. But so that everyone understands, that agreement was entered into, essentially, the end of June. So the 90 days or the first quarter report would be due approximately October 1. []

RON STEGEMANN: Right. I believe it started on July 2. []

SENATOR LATHROP: Okay. So the 90 days or the first quarter have passed. Have you seen a report from... []

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RON STEGEMANN: Dr. McGee? []

SENATOR LATHROP: ...Dr. McGee? []

RON STEGEMANN: No, I have not. []

SENATOR LATHROP: Okay. But you say he was at your place three weeks ago. []

RON STEGEMANN: Approximately three weeks ago with a group of experts that he had brought into the organization to look at where we were at in our implementation process. []

SENATOR LATHROP: Did he provide you with any conclusions relative to or any of his conclusions relative to where you were at in the implementation process? []

RON STEGEMANN: Nothing specific, no. []

SENATOR LATHROP: Did he say anything generally? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: What did he tell you generally? []

RON STEGEMANN: What he said was this first visit will be an overall look at the organization. He asked for specific things that were included within the agreement, the 165 things you referred to. There were things like priority groups for things like behaviors, for things like the use of restraints, for medical issues. We provided him with all of those groups. What he said, initially, was this is kind of a period of baseline; we want to see where you're at now based on what the Department of Justice saw when

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they came in, which would have been over a...almost a year prior to that and then put that up against what we have accomplished within the 165 pieces of agreement that are there. And then we'll be moving forward from that direction. Dr. McGee has been very complimentary of the facility, of the staff within it and of the cooperation that he has received from BSDC in his effort. []

SENATOR LATHROP: Okay. I said 165 things and it may be only 140. But it's a lot, a lot of different things that need to be done. And a lot of them needed to be done in the first 90 days. []

RON STEGEMANN: And there are multiple things within each of those items that need to be done,... []

SENATOR LATHROP: Right. []

RON STEGEMANN: ...many of which were accomplished before we ever had the agreement. []

SENATOR LATHROP: Okay. So with respect to the items that needed to be completed in the first 90 days. Can you just tell me where we're at or tell us, generally, where you're at with respect to knocking out those things that you agreed to with the Department of Justice? []

RON STEGEMANN: I really can't. And part of the reason for that is as you read through that document you will see that there are words used like "adequate," "appropriate." So it will be up to the independent expert to make a determination as to whether or not we've met that. []

SENATOR LATHROP: Okay. I would agree that some of those things are subjective in the sense that they say "adequate" or "proper" or "sufficient." But some things, some

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things that deal with staffing are not so subjective. And as I look through the problems with CMS, as I look through the DOJ agreement and the recommendations from Liberty, the consultants, there are some pretty specific recommendations with respect to staffing are there not? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Can you tell us where we're at with...we were down in Beatrice in what, June or July... []

RON STEGEMANN: Um-hum. []

SENATOR LATHROP: ...if I'm remembering right. Can you tell us where we're at, what improvements you've in the staffing problems, which seem to be part of the core issue at Beatrice,... []

RON STEGEMANN: Sure. []

SENATOR LATHROP: ...where we're at or what steps we've taken in the last 90 days. []

RON STEGEMANN: Okay. We have made significant progress in our staffing of developmental technician positions, the direct care positions. And that's been accomplished through a number of different things, one of which is decreasing the census at the facility, closing some of the homes on campus. As a matter of fact, yesterday we announced the closing of another one of our residences, reallocating the staff that we do have on board. We've done a better job of recruiting and retaining staff. I received a report from our...which is a position that was created through the recruitment and retention funds that were allocated to us--it's that position orientation facilitator. I've asked him for some documentation of that because I thought it was a rather strong statement. But he was willing to go out on a limb and say that he's saved

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at least eight people that probably would have left BSDC had he not been working directly with them. So we're doing a better job within our retention. My assistant administrators and my new administrator for neighborhood services came to me a couple of weeks ago and said, wow, we're full of staff on first shift. My response to that was, that's kind of difficult to believe. And we have to take a look at how many staff do we actually need on first shift now based on who we are and the size that we are. But it's been a long time since we haven't had any noticeable number of vacancies on first shift. Our second shift staffing has also improved as well. The most recent overtime information that I got from our human resources department had our mandatory overtime during a two...the most recent two-week period down to a little over 28 hours. And our voluntary...or the overtime as a whole was reduced by 600 hours from the previous pay period. So that gives us indications that our staffing at the direct care level is improving. []

SENATOR LATHROP: The direct care level being the people that are face-to-face with the...constantly face-to-face with the residents. []

RON STEGEMANN: Eight hours a day, yes, sir. []

SENATOR LATHROP: When you say that the overall, because the mandatory, I think I've been through this before with you,... []

RON STEGEMANN: Um-hum. []

SENATOR LATHROP: ...the mandatory overtime are the people who don't have a choice in the matter. And then we have some people who actually volunteer for overtime so that they don't get forced into a different shift. []

RON STEGEMANN: Not solely because they don't get forced into it, because they like the money. []

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SENATOR LATHROP: Some people do it just for the money. []

RON STEGEMANN: Right. []

SENATOR LATHROP: But some people are doing it to avoid having the employer, Beatrice Development Center, tell them when they have to do a... []

RON STEGEMANN: There is a likelihood some of those folks are doing it for that reason, yes. []

SENATOR LATHROP: Okay. So you said we're down 600 hours. How many hours did we have in overtime in total? []

RON STEGEMANN: I believe there was approximately 3,600 hours of overtime. []

SENATOR LATHROP: And that's over what period, a two week period. []

RON STEGEMANN: Two week period. []

SENATOR LATHROP: It still, I mean these reports the Department of Justice, the agreement talk about a substantial or getting overtime down to minimal or no overtime. Not quite there would you agree? []

RON STEGEMANN: No overtime will not happen. I've been there 19 years. That has never happened. But we can minimize and we can reduce it further. []

SENATOR LATHROP: Yeah, you can go a long ways from where you're at. []

RON STEGEMANN: Yes. []

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SENATOR LATHROP: You mentioned the retention and recruitment money that was provided for by the Legislature. At the end of our last session we made an appropriation or allocated or earmarked about \$1.5 million for that purpose, did we not? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Tell me what you've done with that. []

RON STEGEMANN: That money was used for recruitment efforts. Each new developmental technician position, not any of the rest of the positions at the facility, but each new DT staff, if they made it through their first six months, could receive \$500 in incentive pay. For their first year of employment, successful employment, they would receive an additional \$1,000 for that at the time of their year evaluation. And at the end of the second year evaluation they would receive \$2,000. So they had an opportunity for two years of employment to receive an additional \$3,500 in incentive pay. []

SENATOR LATHROP: Okay. Did...was it all used? That sounds like a recruitment rather than a retention strategy. []

RON STEGEMANN: Okay. []

SENATOR LATHROP: Was it all used for recruitment or did you do something with respect to retention too? []

RON STEGEMANN: For retention for the developmental technician positions only, none other at BSDC, we provide for a satisfactory or above performance \$1,000 incentive pay at the time of their annual evaluation, for satisfactory or above performance. []

SENATOR LATHROP: Was any of that...were any of those dollars used for other than

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direct care staff? For example, you didn't use any of that \$1.5 million to find a psychologist or a psychiatrist or a neurologist or a speech therapist. []

RON STEGEMANN: No, sir, not that I'm aware. []

SENATOR LATHROP: All of it was used for direct care staff. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: How much of that \$1.5 million have you spent on recruitment and retention of direct care staff? []

RON STEGEMANN: I have not seen those figures. []

SENATOR LATHROP: You don't have any idea? []

RON STEGEMANN: Well, I can...there's another piece to it that we didn't quite get to for the retention piece. []

SENATOR LATHROP: Okay, go ahead there. []

RON STEGEMANN: One of the things the staff were telling us at the point in time in which the money was allocated to us was that they were shot, that they were tired, that they had had to work too much overtime. So one of the undertakings that we did was to bring temporary agency staff on board to alleviate them having to work the overtime. So to do that we sought out certified nursing, agencies that had certified nursing staff with them with the understanding that they would have a certain level of skill in taking care of people. When they came into the organization we would have to add some DD training to that. We could get them out on the floor as quickly as possible so they could alleviate the issue of having work overtime for a staff that were there. []

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SENATOR LATHROP: So, I guess, what you're telling me is that some of the dollars that we set aside for recruitment and retention of staff you actually used to bring in temporary staff. []

RON STEGEMANN: As a method of retention for the staff we had. []

SENATOR LATHROP: Yeah. The rationale employed in order to justify using that money for temporaries was we're improving morale by reducing overtime. []

RON STEGEMANN: Right. []

SENATOR LATHROP: Now I'll ask you how much of that \$1.5 million do you think you've spent, if those are the three purposes to which the money has been put. []

RON STEGEMANN: I would guess probably in the neighborhood of about \$1.1 million. []

SENATOR LATHROP: How much of that was spent on temporary help? []

RON STEGEMANN: I believe in the neighborhood of \$900,000. []

SENATOR LATHROP: So in terms of recruitment and retention, which was the original purpose of the money, we probably spent \$200,000 in bonuses. []

RON STEGEMANN: At this point, because it was over a two-year time period that the money was to be distributed. []

SENATOR LATHROP: Has all that money been distributed or are you giving me numbers of dollars distributed and earmarked for some purpose? []

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RON STEGEMANN: No, the plan was designed for the \$1.5 million over a two-year period. So the remaining then is still available for the recruitment and retention stuff that I had spoken about before--the... []

SENATOR LATHROP: Okay. []

RON STEGEMANN: ...satisfactory performance incentive bonuses. []

SENATOR LATHROP: Let me make sure I understand it. You spent \$1.2 million so far?
[]

RON STEGEMANN: About...again, I haven't seen the actual figure, I'd guess about \$1.1 million. []

SENATOR LATHROP: One point one and \$900,000 of it has gone to temporary help. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And the balance has actually been given to direct care staff to either bring them in or retain them. Is that the case? []

RON STEGEMANN: Correct. I am not aware of it being spent for any other purpose. []

SENATOR LATHROP: Okay. And you would then have a balance of about \$300,000. []

RON STEGEMANN: Three hundred thousand to four hundred thousand dollars. []

SENATOR LATHROP: Okay. Liberty provided, as we've talked about, they've provided a report and you've read it, obviously, as have I. And they made a number of

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recommendations. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Do you know how many of those recommendations you've actually followed? []

RON STEGEMANN: We recently reviewed the recommendations that Liberty had within the report, I believe there was 252 of them. And within that review we figured that there was about 11 or 12 of them that we had not either implemented fully or in the process of implementing since the time that Liberty came on board with us. []

SENATOR LATHROP: All right. One of the...I was just thumbing through that over the lunch hour. And one of the recommendations was that we hire two behavioral analysts. []

RON STEGEMANN: Was it two or five? []

SENATOR LATHROP: Might be five, a number of behavioral analysts, that we put on five behavioral analysts. []

RON STEGEMANN: Board certified behavioral analysts. []

SENATOR LATHROP: And they're hired and on staff. []

RON STEGEMANN: They are not. []

SENATOR LATHROP: Okay. (Laugh) Then you were correcting my terminology and not agreeing with me. []

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RON STEGEMANN: Just the number, yeah. []

SENATOR LATHROP: Okay. The recommendation was for five behavioral analysts. And the reason I ask you about that particular recommendation, Ron, is that it said terminology like--we think it's imperative or it's...it was a very, very strong recommendation, seemed to be a centerpiece of their staffing requirements. []

RON STEGEMANN: It's a supply and demand issue. I believe there are three in the state of Nebraska. []

SENATOR LATHROP: Okay. How many of them do you have working at BSDC? []

RON STEGEMANN: None. []

SENATOR LATHROP: Okay. []

RON STEGEMANN: We did...we have utilized the services of one through contract for a period of time. []

SENATOR LATHROP: All right. Let me just go back and ask you how many vacancies do we have at the direct care staff level presently? []

RON STEGEMANN: We just changed 66 vacancies that were direct care level, and we created new positions that are our shift supervisor positions. []

SENATOR LATHROP: When did you do that? []

RON STEGEMANN: We posted that position approximately four weeks ago. []

SENATOR LATHROP: Is that actually been undertaken? []

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RON STEGEMANN: Yes. []

SENATOR LATHROP: I mean you're in the process of doing that. []

RON STEGEMANN: It closes...those positions close this afternoon at 4:00 for people to apply for. []

SENATOR LATHROP: So they haven't been filled. []

RON STEGEMANN: No, sir. []

SENATOR LATHROP: Okay. Then let me ask you just presently, without respect to that new level of management that you're going to put into place,... []

RON STEGEMANN: Okay. []

SENATOR LATHROP: ...when Liberty left in April they said we had 100 vacancies in direct care staff. How many vacancies do we have in direct care staff now? []

RON STEGEMANN: We have approximately 100. But I don't know where Liberty got that number. []

SENATOR LATHROP: So you'd say that we still have 100 vacancies. []

RON STEGEMANN: At present? []

SENATOR LATHROP: Yes. []

RON STEGEMANN: If you include those 66 positions, yes. []

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SENATOR LATHROP: Yeah, okay. Which is...those don't even start until sometime maybe next week, right? []

RON STEGEMANN: It will be a while for the hiring process to take place, yes. []

SENATOR LATHROP: Okay. So it doesn't sound like we've made a significant dent in the shortage of direct care staff... []

RON STEGEMANN: Our census... []

SENATOR LATHROP: ...or am I missing something? []

RON STEGEMANN: Census has continued to be reduced. I don't know where Liberty got their number from. []

SENATOR LATHROP: You agree it was in there. I'm not misrepresenting the report. []

RON STEGEMANN: There may be a number in there, but I'm not sure how they arrived at that number. []

SENATOR LATHROP: Okay. You mention the census. What is the census at Beatrice? []

RON STEGEMANN: I believe it's 256. []

SENATOR LATHROP: What was it when we were last down there? That sounds like a number that was pretty close to what it was the last time we were there. []

RON STEGEMANN: It probably isn't terribly far off. It was probably around 260 or low

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260 somewhere. []

SENATOR LATHROP: Okay. So you've had three or four or five people leave since we were there this summer. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And what about the professional positions. There were psychiatrists, neurologist, there was a lot of criticism about not having a neurologist on staff, was there not? []

RON STEGEMANN: Not necessarily not having one on staff, but not having more hours available from one. []

SENATOR LATHROP: Tell us where we're at with respect to the professional staff. And maybe if you can do it in terms of where, making a comparison to where we were in April or when Liberty Mutual...or when Liberty...I keep calling them Liberty Mutual, when Liberty consultants left. []

RON STEGEMANN: It's difficult for me to go back and grab ahold of that time period and make any kind of a comparison. I will tell you what we are doing now in terms of bringing those types of professional staff on board, if that will help. []

SENATOR LATHROP: Okay. []

RON STEGEMANN: Okay. What we've done with the neurologist position is we've increased our neurology hours by 50 percent. With the contracted neurologist that we had on board and have had for a number of years we increased our neurology clinic times. []

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SENATOR LATHROP: Does that increase to 50 percent get us to the recommended level of neurology hours? []

RON STEGEMANN: Our independent expert has not given us a number of hours. He will determine if that's adequate, appropriate. []

SENATOR LATHROP: But the DOJ report addressed the number of hours you need, did it not... []

RON STEGEMANN: They did not give us... []

SENATOR LATHROP: ...for neurology? []

RON STEGEMANN: ...a number. []

SENATOR LATHROP: Pardon me? []

RON STEGEMANN: They did not give us a number. []

SENATOR LATHROP: Okay. So you're waiting to find out if an increase of 50 percent is sufficient? []

RON STEGEMANN: Right, and that will be with the work we do with Dr. McGee. []

SENATOR LATHROP: The report may not have specified exactly how many hours, but it did tell you how many hours or how much care the patients at Beatrice need from a neurologist, did it not? []

RON STEGEMANN: It uses words like "appropriate", "adequate". []

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SENATOR LATHROP: No? They didn't say an annual exam? Pardon me? I'm trying to do this off of recollection and... []

RON STEGEMANN: Okay. []

SENATOR LATHROP: ...and like you, there's a lot of information out there, Ron. []

RON STEGEMANN: There is. []

SENATOR LATHROP: I'm not to trick you. []

RON STEGEMANN: Sure, I understand. []

SENATOR LATHROP: I am just trying to get a good sense of neurology, for example, I thought it was the Department of Justice agreement that said we will have...do this with respect to our patients because of their risk of epilepsy and so forth. []

RON STEGEMANN: Right. []

SENATOR LATHROP: Do an examination, like an...in a pretty short period of time and annual exams after that. []

RON STEGEMANN: We believe that our, and perhaps this will help. We believe that our increase in neurology hours for our neurology clinics will meet the intent of the DOJ agreement. []

SENATOR LATHROP: That is what I'm looking for. []

RON STEGEMANN: Okay. Dr. McGee will tell us if indeed that's, by his opinion, true. []

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SENATOR LATHROP: Okay. Why don't you help me with the other specialists. []

RON STEGEMANN: Sure. []

SENATOR LATHROP: We need nurses, speech pathologist, occupational therapist. Can you go through that with me? []

RON STEGEMANN: Another one of the issues was psychiatry, in the area of psychiatry. We had a firm that we contracted with for our psychiatric service. And they, in essence, said...they're from Lincoln. They said, we can make as much or more money sitting here in Lincoln as driving down to Beatrice, so they declined to recontract with us for this year. So at present we are without psychiatric services specifically, and that is being covered by our medical staff. We have... []

SENATOR LATHROP: Before you move on, I think I read something in the report that specifically said you needed a psychiatrist and specifically said they didn't want the psych services provided by medical staff. []

RON STEGEMANN: It does. []

SENATOR LATHROP: It does. So how long have you been without a psychiatrist, Ron? []

RON STEGEMANN: Since July 1. []

SENATOR LATHROP: And what efforts are being undertaken to bring a psychiatrist into Beatrice? []

RON STEGEMANN: Where we're at now is our medical director, Dr. Alfred Harrington, has negotiated with two psychiatrists. And we believe that those contracts will be signed

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off on. And what we'll have is psychiatric services two times a week with those gentlemen. []

SENATOR LATHROP: Did the DOJ recommend a full-time psychiatrist? []

RON STEGEMANN: Again, they don't give hours, full-time. They say "adequate" and "appropriate." []

SENATOR LATHROP: And you think two hours two days a week is going to be adequate and appropriate? []

RON STEGEMANN: Based on the number of individuals we have who have psychiatric needs, yes. []

SENATOR LATHROP: Go ahead. []

RON STEGEMANN: Additional positions--physicians, we did bring Dr. Alfred Harrington on board as our medical director. I'm not sure if he would have been there at the time that you visited this summer. We have had a nurse practitioner, half-time nurse practitioner that has left. And so we have recruited and retained the services of a full-time nurse practitioner who has certification both on the medical and mental health side. And she will join us at the end of October. So that increases our medical staff by a position of one. The other areas that we are in the process of bringing contracts in, and I have to take some back with me to our contract folks when I leave here today, is in the area of therapies. And very simply, that comes down to a supply and demand issue as well, and what we have the capability of being able to pay those folks, and that's in the area of physical therapy, occupational therapy and speech therapy. []

SENATOR LATHROP: Can you...I'm going to ask you a question about the vacancies that we have because it might be easier for me to understand what we haven't filled

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than to have you tell me kind of individuals that you've put on. []

RON STEGEMANN: Okay. []

SENATOR LATHROP: But we talked about this the last time we were down in Beatrice. And you told me that there is a ceiling on what you can offer to someone if they want to...when you're trying to recruit a nurse or a physical therapist or something like that. Am I right? []

RON STEGEMANN: The ceiling is within the personnel created structure for each position. []

SENATOR LATHROP: Right. And that is established by whom? []

RON STEGEMANN: As a...within my discussion that's done by State Personnel. []

SENATOR LATHROP: So you're having trouble, just generally you're having trouble finding therapists that will come down to Beatrice because you can't offer them enough money, is that true? []

RON STEGEMANN: I can now. []

SENATOR LATHROP: All right. Tell us how come you can now? Did you go get more authority? []

RON STEGEMANN: Not necessarily more authority, but what we have to do within all of this is we have to go beyond what we're able to do within our state personnel system and offer them employment through contracts. []

SENATOR LATHROP: Yeah. (Laugh) I don't even know where to start with that one.

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The personnel, State Personnel decides what a physical therapist is worth. You can't find somebody for that and so you go make them a contract or have them come in and do the same work but you pay them more than probably what physical therapist would ordinarily get paid in an employment situation. []

RON STEGEMANN: Not necessarily, it may be the same through the contract. []

SENATOR LATHROP: So if a physical therapist, for example, is worth \$45,000 a year, for example, at...we can't pay that because of our personnel practices. So you make them a contract employee. []

RON STEGEMANN: Yes. As an example, recently had a speech therapist who left our employment to go to work for Beatrice Public Schools. She left for a pay increase of approximately \$15,000 a year and she doesn't have to work summers. []

SENATOR LATHROP: So did you hire her back? Is that the rest of the story? []

RON STEGEMANN: No. She went to work for the school. []

SENATOR LATHROP: And you just lost her. []

RON STEGEMANN: However, a lot of those therapists like to have businesses on the side and then contracts on the side. So it's very possible we can get her back through contract for work during the summertime. []

SENATOR LATHROP: Okay. Why don't you give us a list of the openings that you still have, the vacancies. And you've already gone through the direct care staff. Can you tell us what vacancies you still have. []

RON STEGEMANN: What Director Wyvill handed me was...doesn't include information

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for vacancies, it just shows filled. But we're actively recruiting for 27 developmental technician IIs. I believe, by the end of today we're recruiting for four developmental technician mentors, and those positions will be offered to BSDC staff today. And we're recruiting for the 66 developmental technician shift supervisors. We're currently recruiting contracts with two psychiatrists. I am recruiting for an active treatment administrator position. We are actively recruiting for one physical therapist, and in the process of creating two contracts...or contracts with two physical therapists to fill the need. Our psychology director position is being filled by contract. We have two psychologist positions that are filled by contract. []

SENATOR LATHROP: Will they be...will they work 40 hours a week under these contracts or are they just coming in a half day or... []

RON STEGEMANN: The two psychologist positions will be full-time. This psychology director position is about a quarter time. We currently have one quality improvement administrator position under contract. We are recruiting for one social worker II position. We are recruiting for one speech pathologist position and have two speech pathologists under contract. We are actively recruiting three activity specialists in our vocational department. And those are newly created positions. We are actively recruiting for an investigations administrator. We are actively recruiting for four treatment team leaders, three human services treatment specialists, two human service treatment specialist I's, three laundry workers, four nurse II positions, and one chief of security. []

SENATOR LATHROP: Will that get you manned? Will you be fully staffed at Beatrice if you get all those people there? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And will you satisfy the Department of Justice with...if you put all those people on? []

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RON STEGEMANN: Yes. []

SENATOR LATHROP: And do you need to put all those people on to satisfy the Department of Justice? []

RON STEGEMANN: All of them, no. []

SENATOR LATHROP: Well, you might not...they may not care about the laundry guy. []

RON STEGEMANN: Yeah. []

SENATOR LATHROP: But you need all those trained folks. []

RON STEGEMANN: Absolutely. []

SENATOR LATHROP: Okay. So you need them for the DOJ, you need them for CMS, and they're also the recommendation of Liberty, who we paid. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Do you have the budget to put all these people on? If they all came to your door and the qualified showed up and were ready to work could you put them on? []

RON STEGEMANN: That I can't tell you. I know what I've been told by those above me is bring them, fill the positions. []

SENATOR LATHROP: Okay. So you've had some conversation with whom about putting all these folks on? []

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RON STEGEMANN: Director Wyvill and Chris Peterson. []

SENATOR LATHROP: Okay. And they've said, hire whoever you need to hire, get them on. []

RON STEGEMANN: Yes. []

SENATOR LATHROP: Okay. I just have a few more questions for you and then we'll...I'll kind of step out of the way and let everybody else ask a few... []

RON STEGEMANN: Okay. []

SENATOR LATHROP: ...or whatever questions they might have. But you've been the director now for a year. You kind of came in, in the middle of a very difficult situation, admittedly. Do you have sort of priorities or goals or a vision for how you're going to bring Beatrice out of a very difficult place where it has...stands to lose its certification to CMS. Do you have a vision or a goal that you can share with us about how you intend to do that, Mr. Stegemann? []

RON STEGEMANN: Sure. Almost everything that you'll see within the conditions of participation, and particularly those that have to do with active treatment are attached to staffing at the facility in many ways. It's difficult to provide active treatment. And active treatment starts when...from the time a person wakes up to the time that they go back to sleep again and starts all over. You don't go to a building for active treatment. You don't go to a room for it, it happens throughout your waking hours. So active treatment is a huge component of what we need to be doing at the center. In order to do that and do it to a level at which CMS requires and that we think each person deserves we need to make sure that we have adequate staff on board to do that. So one of the big priorities over the last year has been to bring staff on board. Specifically we focused a lot on

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direct care staffing. The Legislature was able to and provided us with additional funds to assist us in that process. And we appreciate that. Our focus now that we are doing better on our direct care positions, we're not where we need to be at. We need to continue to recruit and retain staff and make that a much improved process for those folks, is that we need to fill those specialty positions, those therapy positions, because that's a key component to what active treatment is. We have many people who have excellent experience with folks with developmental disabilities. They know them, they know what makes a good day for them and what constitutes a bad day. But we need to have those specialists on board in order to give us the expertise that's demanded by CMS and that each person deserves in order to have the services as designed for each individual person. So that's the focus that we have now. Beyond that, my initial quest then is to improve those active treatment services based on the staff that we get on board, continue to improve our systems so that we can meet all eight conditions of participation with CMS. And that comes through staffing, it comes through the training of staff, making sure you have qualified, knowledgeable staff, ensuring that you have adequate supervision at the service delivery point. And that's the issue with the creation of the 66 shift supervisor positions is so that there is someone there working side by side with the developmental technicians in a management supervisory role that can ensure that those services are being provided regardless of where a home manager, who has a much broader range of supervision might be. So they'll be working directly within them. And that's a big piece of where we felt that there was a gap between what we teach staff needs to be done with each individual and what actually was happening out on the living unit level. The Department of Justice brought it to our attention, CMS brought it to our attention. We've known it based on our interactions with them. And so this was our method of increasing the supervision at the line level so that we're ensuring that services are being provided. []

SENATOR LATHROP: By the way, as you fill those 66 positions that are supervisory, you're going to take most of them from the DT staff. You might have some people from outside apply for it. But generally, you're going to...you're recruiting from the DT staff. []

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RON STEGEMANN: Right now it is an internal posting only. And the idea is that we dig into that commitment, that expertise, that knowledge we have at the DT level and allow them the opportunity to grow and expand and become a part of the management piece. So you're correct. []

SENATOR LATHROP: Okay. And that will necessarily increase the number of vacancies in the DT openings at Beatrice. []

RON STEGEMANN: Right. And we will fill those positions. []

SENATOR LATHROP: All right. The thought I had as I was reading all of these recommendations from CMS to...or the problems that were identified by CMS, the recommendations or the promises we made in the DOJ report and then the recommendations in the Liberty report is this is going to cost some money to do. []

RON STEGEMANN: Yes, sir. []

SENATOR LATHROP: Have you requested more money for the Beatrice Development Center. []

RON STEGEMANN: I believe there's been an increased request of \$2.5 million over the next biennium. []

SENATOR LATHROP: Pardon me? []

RON STEGEMANN: Each two years of the next biennium. []

SENATOR LATHROP: So an increase for Beatrice of \$2.5 million over two years. []

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RON STEGEMANN: I believe each of two years. []

SENATOR LATHROP: Each of two years or \$5 million over the two year budget period.
[]

RON STEGEMANN: Yes. []

SENATOR LATHROP: Did you make that request? []

RON STEGEMANN: I made that request along with Director Wyvill and Chris Peterson.
[]

SENATOR LATHROP: Do you think with that additional money you can meet and fill all these vacancies or is it going to be used for...some of it's operational. You might have roof that leak now that you have to fix. Is it all going to go to personnel? []

RON STEGEMANN: The majority of our budget is in personnel, it is in personal services. If the roof leaks, we pay rent on the roof and they take the repairs out of the rent. So the two biggest cost factors for BSDC and by far the largest cost factor is the amount of wages and benefits that we pay folks. []

SENATOR LATHROP: You said that you made the request. Do you know if it showed up in the preliminary budget that came out last week? []

RON STEGEMANN: I don't know that for sure. []

SENATOR LATHROP: You haven't looked at that or been told? []

RON STEGEMANN: I haven't been shown that, no. []

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SENATOR LATHROP: Okay. I think that's all I have. Oh, I'm sorry. Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Thank you for your presentation, although I wasn't here for a little bit of it. The concern that I have in the amount of staff that you're going to need is about 125 at least. Do you feel that you'll be able to get that many hired in this short period of time to accomplish what we need to get to? []

RON STEGEMANN: Short period of time? []

SENATOR STUTHMAN: Well, I don't know what time you're...you'd like to have them come to work tomorrow. []

RON STEGEMANN: Sure. []

SENATOR STUTHMAN: And I would like to see that, too, but that isn't possible. []

RON STEGEMANN: I think the best...what we can do within all that is to gradually increase our staffing number. BSDC constantly recruits for direct care positions. I can't think of a time ever when we weren't recruiting for direct care positions. We are making headway now with those specific therapy positions. And we're having to do it, unfortunately, through contracts in order to get those services provided for the individuals. That will be a more difficult process. And it will take some time and it will take money. []

SENATOR STUTHMAN: Okay, thank you. And I wish you the best. []

RON STEGEMANN: Thank you. []

SENATOR LATHROP: Oh, I'm sorry, Senator Harms. []

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SENATOR HARMS: Thank you very much, Senator Lathrop. And, Ron, thank you for coming. I noticed in a report that you just gave us that deals with service contracts... []

RON STEGEMANN: Okay. []

SENATOR HARMS: ...or January 2, '07 through September 30, '08. I notice that you have hired a couple of organizational development consultants, Buehler, if that's the correct pronunciation, and Sanchez (phonetic). []

RON STEGEMANN: They are no longer with us. []

SENATOR HARMS: Well, I understand that. []

RON STEGEMANN: Okay. []

SENATOR HARMS: But what I'm wanting to know is, what was the purpose of and what did they accomplish for you as organizational development consultants? And what were you trying to accomplish? []

RON STEGEMANN: I did not bring those folks on board. Those were brought on board by our prior acting CEO. []

SENATOR HARMS: Okay. So what was the purpose? Do you know? []

RON STEGEMANN: As I understand the purpose for that was to look at our organization as a whole to find out where the strong and weak points were within the organization, in order to report that back to the then acting CEO. []

SENATOR HARMS: And what did they find? []

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RON STEGEMANN: I did not ever see a report from those folks. I was not in this position at that time. []

SENATOR HARMS: Do we know whether we have a report? I think you paid, what, \$18,000 or \$20,000 for it. Surely we have a report somewhere. []

RON STEGEMANN: It might be a better question for Director Wyvill. []

SENATOR HARMS: Okay. I wanted also to talk to you a little bit about as we downsize this particular program, do you feel comfortable we have the right community-based programs to put your clients into and that we're going to have the right supervision and the right control. []

RON STEGEMANN: At this time, my knowledge of the community-based programs is probably five or six years old. At one time I was involved with the OTS program, and so I did outreach and went out to a number of different community programs. So I can only base my response to that question on the difficulty we've had in having folks go from BSDC to community-based programs, particularly those that have some challenging behavioral concerns. At present time, there are some inadequacies in being able to provide specifically for those folks that do have challenging behaviors. []

SENATOR HARMS: So are you supporting then that continued movement has increased the number of clients in Beatrice into community-based programs? []

RON STEGEMANN: Absolutely. []

SENATOR HARMS: And how are we going to control that? And how are we going to supervise that? And how are we going to make sure that we have an adequate program? []

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RON STEGEMANN: I believe that's a question better responded to by Director Wyvill. []

SENATOR HARMS: Okay. When I look at a number of the reports and documentations, Beatrice has been studied a great deal. You've spent a lot of money in consultants and reports. And you've had a lot of people look at you very carefully. It's pretty clear what you have to try to accomplish in a very short period of time. But as I look at that and as I have studied this it's really clear to me that a lot of the issues that you have from your door down throughout your system (inaudible) management issues, management's concerns or having the right people to manage. What are your thoughts about that? Is that a correct observation? []

RON STEGEMANN: There are management issues that do need to be addressed. []

SENATOR HARMS: Okay. And so what are some of those management issues as you see them? As the CEO, what are some of those issues? []

RON STEGEMANN: I talked a little bit about the issue when you are short staff, how that kind of expands into everything else. When you are as short of staffing as BSDC was at one point, after 2006 or at the time of 2006 when CMS came, and you were looking at a shortage of folks to be able to hire, in general, from your labor pool, it becomes difficult in some perspectives to be able to manage effectively the people that you have on board. If you take performance corrective actions, if you terminate individuals because they are lacking in performance that's a person gone. I believe, with the numbers that we have now we can correct that. And one of the positions I've brought on board is our residential services administrator, Dan Hyman. He has years of experience in ICF/MR settings, both in Ohio and in Florida. And one of the reasons that I brought him on board is his experience in being able to come into an organization, work with the management structure that exists, make sure that the managers know what the expectations are of their performance, and then begin to correct that performance throughout the organization. []

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SENATOR HARMS: So how did we get ourselves in this position with regard to the management structure? I mean, just in some cases it's not quite there. So how did we allow it to get there, I mean, as you look at it. I realize you've only been there, you know, a year. []

RON STEGEMANN: Sure. []

SENATOR HARMS: But when you look at it, how did we get ourselves in this position? []

RON STEGEMANN: Having been there a year, I can't tell you how the management piece got to where it was a year ago when I started. []

SENATOR HARMS: In one of the previous hearings that we had, we have people within our own state that go in and look at it. I asked them the same question. And it's an amazement to me that no one knows how to put their finger on that issue. How did we get there? How do we resolve it in the future? And how can we protect that it never happens again? []

RON STEGEMANN: One of the reason why... []

SENATOR HARMS: What are your observations of that? []

RON STEGEMANN: I can give you a, I guess, just a personal point of view from that. []

SENATOR HARMS: That's fine. []

RON STEGEMANN: One of the reasons why I wanted to bring someone in from outside of the organization was to get a fresh set of eyes on our management structure. You will

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find probably, if you went through the amount of seniority that exists among our managers, you will find that it's probably very high. They've been with the organization for a number of years, and they have experiences that have led them to the point where they are now. Typically, you don't start at BSDC as a manager, you work into that at some point. But we have had some that have come in at the manager level. So by bringing someone in new to the organization it releases that person from any sort of relationships that exist between the folks that are there now. They can go into it with unbiased relationship ties, with a new set of eyes, with a set of performance expectations that I've worked on and have provided with him, and then those things can be dealt with accordingly. When you work together with people for a long time you develop certain relationships. And I believe that may be a contributing factor to some of our management issues that exist now, not just management but organizationally as a whole. []

SENATOR HARMS: I would agree with that. I think it is very difficult to do. I've experienced that myself and in different organizations so I do understand that aspect of it. In regard to the present organizational structure that you have,... []

RON STEGEMANN: Yes. []

SENATOR HARMS: ...are you satisfied with that structure, that it's an adequate structure? And if you had the opportunity, would you reorganize that or develop it in some other form? []

RON STEGEMANN: I believe I do have the opportunity. I don't believe that our structure is static. There are some...still areas that I have questions on. And as I bring those administrators in and begin to be able to form a team with those folks, I'm still a couple short, I think we need to take a fresh look at the organizational structure and make sure that what I've set up, based on the recommendations that Liberty gave us, is indeed going to be a functional structure for the facility. []

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SENATOR HARMS: So what are those areas that you would look at? What are the areas that you have concerns about? []

RON STEGEMANN: Specifically we have areas like nursing and the therapies under our active treatment division. Is that the best fit for those folks? Given that they're involved with each person's day-to-day activities and they have a piece of that within the IDT it does fit to a certain extent. Does it work better under the medical structure within our organization? That's a piece I'm not quite sure about and will continue to work on and look at. []

SENATOR HARMS: As you look at your management structure within the organization, do you feel that you have it...have the appropriate people in the right places through the structure? []

RON STEGEMANN: I'm getting them there. []

SENATOR HARMS: Pardon? []

RON STEGEMANN: I'm getting them there. []

SENATOR HARMS: How are you getting there? []

RON STEGEMANN: Well, I believe we had in terms of within neighborhood services, which was where a majority of the staff worked is within neighborhood services. The bringing on of Dan Hyman as the administrator for those has, with...in my opinion, has been a very positive move. Underneath him are three assistant administrators for the three different areas that we have. Those are three very strong individuals that rose out of what CMS kind of left for us when they walked out of the door in 2006. There were a number of us that stepped up and tried to do the best job we possibly could for BSDC

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with some outside assistance. And these are three folks that stepped up and were outstanding in that process. And they're very dedicated and committed and they want to be successful. []

SENATOR HARMS: I know when we were at Beatrice, as well as the people who have come here to testify, it's really clear that, at least to me it's clear, that the culture of Beatrice has to change in order for you to accomplish what you want to accomplish. []

RON STEGEMANN: Yes. []

SENATOR HARMS: I applaud what you're trying to do here. How are you looking at changing that culture, and what type of planning are you doing to get to that change. []

RON STEGEMANN: One of the ways that we look at changing culture is by being out there amongst the staff, amongst the individuals throughout each day. And so a lot of that, and again while I don't want to put too much on the fact that I've brought a person on board, a lot of our discussion with Dan Hyman prior to him coming to work there was--talk to us about cultures, what kind of cultures have you been involved with, what type of changes have you had to make in organizations. And...so that was one of the things that I've charged him with. And he has reported back to me we do have several cultural issues that we need to change. []

SENATOR HARMS: What are those? []

RON STEGEMANN: They are issues that you will see throughout the reports. How are people spoken to, how are they provided services in terms of how the staff interact with them? Are they asked to do things, are they told to do them? Are we making sure that we put ourselves on an even level with the individuals, that it's not staff are up here or professional staff are up here and clients are down here and we're talking down to them. So language is a huge piece within all of that. So it's very important that the assistant

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administrators and the administrator for those services focus on and take a look at the daily interactions that happen between everyone in the organization and the clients and make those specific changes. []

SENATOR HARMS: Are you familiar with your staff development program that you have established that they use for staff development that everybody goes through? []

RON STEGEMANN: Yes, yes. []

SENATOR HARMS: What's your evaluation of that program? []

RON STEGEMANN: Staff development provides, I think, a good quality training program for our new hire staff to give them the basic skills and knowledge that they need in order to get started on their career as a developmental technician. Where we need to focus our attention, most likely, and I spoke with our coordinator just recently, is on the training and education of veteran staff, so it's ongoing training that we need to be able to focus on. Again, going back to staffing if you don't have enough staff out on the floor it's pretty difficult to pull anyone out and do some ongoing training with them. So... []

SENATOR HARMS: I noted thought, I did visit with the staff. And they are just a little frustrated with that particular issue because it's really hard for them to...they have to chase them down to make sure that they can get it down to meet what the criteria is. Now, I'm not trying to trap you with this. But in talking with CMS yesterday one of the things that they talked a little bit about staff development. I wish I would have known that before I talked to your people. They did bring forward the fact that some of the concepts and some of the philosophy and some of the ideas that we have are antiquated and unappropriate and they need to change. So that's why I'm...I was wanting to...getting to staff development. I'm not trying to set you up in any form or manner. []

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RON STEGEMANN: Sure. []

SENATOR HARMS: But it's something, I think, you're probably going to have to look at. You're going to have to go in and evaluate that carefully because they were pretty...they were surprised with what was really taking place. And it wasn't...times have changed a lot. And maybe the adjustments haven't been made there. So I would surely encourage you to make sure that that's accomplished, because when you set the stages for these people and if you aren't giving them the newest thoughts and the newest ideas of how to handle and treat and deal with their clients in many cases it doesn't work...

RON STEGEMANN: Right. []

SENATOR HARMS: ...well at all. So... []

RON STEGEMANN: I appreciate that. And that's one of the difficulties we have in dealing with CMS is they'll say they're outdated, they're antiquated, they're not up to national standard practice. But then they won't tell you what is. So we have to go out there and find that for ourselves, and we'll certainly work on doing that. []

SENATOR LATHROP: That's an interesting comment to make, because when I was reading the Liberty report they talked about contemporary, prevailing practices. Anybody in the healthcare industry is familiar with the phrase "the standard of care." []

RON STEGEMANN: Um-hum. []

SENATOR LATHROP: And I did get the sense as I read through the...particularly the Liberty report, that there is a...John...Senator Harms is exactly right. They came in and said, you know, we were using restraints way more than anybody should have. We kind of had some practices that might have been good 20 years ago, but that's not how you

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do things today with the standard of care. And as I was reading through the recommendations of Liberty it seemed to be get your people out and get them to some seminars. Get people out and get them exposed to what the national standard is and what everybody else is doing in the country because we seem to stay at Beatrice and no new ideas penetrate the walls. And we keep doing things the old way. []

RON STEGEMANN: Well, up until two years ago we had the Sharing Our Best Conference at BSDC. And they came to us and shared those ideas. So it's...having been at Beatrice and having had some contact with the outside and being able to attend some conventions and other things over the years it just seems odd to me that, because we do bring in national level speakers to that conference, that BSDC would not have been aware of those. []

SENATOR HARMS: Well, I would tell you that your...the people that I visited with are very committed to staff development. And so I'm not being critical of them. I just wanted to make sure that, and I think what Senator Lathrop has said, you probably really need to look at that, because eventually that may lead to some other complaints, some lawsuits, other kinds of issues because times have really changed. []

RON STEGEMANN: Sure. []

SENATOR HARMS: And someone need to really do an analysis of that. []

RON STEGEMANN: Thank you. []

SENATOR LATHROP: Senator Adams. []

SENATOR ADAMS: Thank you, Senator Lathrop. Ron, maybe the question that I ask is nothing more than a rehash of what we've already been over here today. But it just stays right here so I've got to get it out. When we spoke to CMS yesterday I left the

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room thinking to myself, we're at a crisis point. Our conversations with DOJ this morning, I didn't leave with quite that heightened a crisis feel, but didn't walk away very comfortable. And I would tell you in all candor that as we have progressed over the summer through all these hearings to your benefit a couple of terms in description of you come out. One is the word "caring" and the other is "knowledgeable." So let me ask a broad question of you, I guess. But I...how did we get to this point? If we're knowledgeable, if we're caring how did we, in your opinion, how did we get to this crisis point? We should have been dealing with long time ago. []

RON STEGEMANN: I agree. []

SENATOR ADAMS: So help me understand. []

RON STEGEMANN: I think you actually answered your question and when you said we should have been dealing with this a long time ago. If you look at the information on where major changes at BSDC have occurred, they have occurred because of outside influence, they've occurred because of the Horacek v. Exon case at which time the census at BSDC declined rapidly until about 1985. And then there's a period of time where the census at BSDC pretty much remains stagnant. There are some decreases, but basically the admissions and placements kind of balanced each other out for a period of time. There were changes within state government that occurred. I can remember a former CEO, at that time the position was the superintendent, saying when I lose control or the ability to be able to manage BSDC I'm done. And there was a period of time within my understanding that BSDC was appropriated an amount of money and they were allowed to spend that money as they saw fit ensuring that they were meeting all the conditions of participation and staying within the federal program. There was a restructuring that occurred at a level. Staff development no longer is controlled by BSDC. Human resources is no longer controlled by BSDC. They work with us, they do a nice job with us, but the reality of it is they have supervisors beyond me that are in Lincoln. So there's a piece of that that all kind of changed within that. I think after that

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period of time, based on the data that I've looked at, and we've looked at a lot of different information. There was a period of time of about 10 or 12 years where BSDC was pretty much on a holding pattern--not much in the way of change of census, not much in the way of outside pressure such as from DOJ, from CMS, from a committee such as this, from Nebraska Advocacy Services--which everyone is involved now. So this is another period of history in which BSDC is the focus of attention certainly within the state of Nebraska, certainly within our part of Nebraska. And so kind of in answer to your question was why weren't we paying attention during that period of time, there just didn't seem to be any clear direction for the facility. Possibly for DD services as a whole it was kind of status quo. []

SENATOR ADAMS: Yeah. []

SENATOR LATHROP: Senator Gay. []

SENATOR GAY: So, Ron, you know I think what you just answered was what we've all been thinking, quite honestly. So we have this disconnect. And I've got several questions. I want to go back to the Liberty recommendations, Department of Justice recommendations. It's an awful lot to give any manager, any company whatever. How did you go about prioritizing or how are you tackling this issue? I mean, they gave you 8 major things and then 144 other issues. How do you go about prioritizing and deciding what you're going to work on? []

RON STEGEMANN: What we do each time those came out, and for example CMS form 2567 that has 431 pages of citations on it or the DOJ report or whatever it is that we need to focus on and pay attention to we've sat down and looked, most recently, at the Liberty recommendation piece to see what it is we've done, what we haven't done, we're (inaudible) steps to limit implement is that we have a system in place and a structure now that I don't have to sit down and look at all of those pieces together. That can be disseminated out to the various department heads and people within those that have

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specific knowledge about each one of those areas. And we can bring that information together in a way so that leadership or a designated community can look at where is our progress within all of that. And that all results in what's called a QI plan for the facility or quality improvement plan. We now have developed a system whereby we are looking at, because we know what CMS wants to see, because we know what Department of Justice is requiring, because we know what the recommendations were that Liberty gave us, we can incorporate those into a quality improvement plan. We can begin to gather data on each one of those issues that are included within that and see how we're doing. So there is a lot there. But if you're in the business, so to speak, you can tell that there's not a great amount of difference between what CMS wants to see, what DOJ wants to see. And Liberty helps to give us a direction or a way that we can go to meet those things. So it seems like a lot all thrown at one time. And maybe because I've been in the middle of it for two years it doesn't seem a lot now, I know it did when we started back in 2006. But we have systems in place now to be able to work with and organize and coordinate the effort and are developing, I'm not going to say it's done yet, but we have developed a QI plan and system with data indicators to be able to track and follow how we're doing with those. []

SENATOR GAY: Okay. Now, do you feel...so you're doing that. Do you feel confident that you're empowered to make these decisions or, you know, decisions have to be made day by day... []

RON STEGEMANN: Yes. []

SENATOR GAY: ...and in your position I can only imagine. But do you feel that you're empowered enough to do that or are you limited? What limits you? And I guess, what obstacles are standing in your way right now that if you could just wave your magic wand and get rid of, I mean, what's out there. We talked about a major staffing problem. To me, I don't know, Senator Adams talked to you about how we got to this point. I think you're going there. But right now even when we went through that list of all these people

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you need, I mean, I don't know how you can...how this works. When you have so many clients that are there that you have to take care of and you're short that many staff, I'm still very concerned because you say you spent \$900,000 of the \$1.1 million on just temporary staff. We need to go hire quite a few people. I'm getting a little worried here because there's a lot of well, you know, the care we're getting and money and just doing the right thing. I'm throwing a lot at you. But I guess, what I'm saying, what obstacles are in your way? How are you going to get rid of them and get some of these things done, staffing particularly. []

RON STEGEMANN: The biggest obstacle, I think we've discussed, is how do we fill those positions given where we're at. Not everybody wants to come to Nebraska to work as a physical therapist. Not everyone wants to come to Beatrice to work as a physical therapist. So we have undertaken the process of beating the bushes to try to get folks that will come in, that have some DD background experience, that have those specialized skills to be able to give us what they can. So if they're not willing to work for us full-time, what can you do for us. So it is a definite concern. I don't know that the obstacle is anything within ourselves that's an obstacle. But there are deficient numbers of specialized services in the state of Nebraska, not at Beatrice, within the entire state. []

SENATOR GAY: So you're talking about psychiatrists, psychologists. []

RON STEGEMANN: Psychiatrists, neurologist. []

SENATOR GAY: And we've been...and that issue we've been dealing with that. I still, though, when you're talking about, and I'm not sure exact...the terminology, but you're talking about line workers. []

RON STEGEMANN: Right. []

SENATOR GAY: And then you have 66 managers you still need to get. []

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RON STEGEMANN: Yep. []

SENATOR GAY: And that was a question too. []

RON STEGEMANN: That's a new position, so we're... []

SENATOR GAY: That's a new position. So, I guess, on that if we can't get the line and you're going to get the managers, you know... []

RON STEGEMANN: Those managers will be doing the line work along with the supervision. []

SENATOR GAY: Okay. So they're actually hands-on, rolling up your sleeves, doing some work. []

RON STEGEMANN: Absolutely, you bet. []

SENATOR GAY: And that was one of the questions I had. I'm a little concerned of where that goes. []

RON STEGEMANN: Right there with them. []

SENATOR GAY: Can you explain the process of hiring the staff. It sounds to me like you're pretty much being creative and saying well, we're just going to...you know, you're not an employer, you're a contractor. You're a contractor, so you're circumventing the process in order to pay what we need to pay to be competitive, is that correct? []

RON STEGEMANN: At times yes. []

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SENATOR GAY: Okay. What is the process if you need to go hire 100 people right now? Walk me through it from the moment you put an ad in the newspaper or how...whatever you're doing. []

RON STEGEMANN: As an employee? []

SENATOR GAY: Yeah. Right now to go hire these people what steps do you have to go through? You said it's become, I think you're outsourcing these things. Who's helping you get these staff members? []

RON STEGEMANN: Well, those agency staff that I talked about and I think we didn't spend all of that \$900,000, I think it was a portion of that. Mr. Wyvill might be able to help with that piece. But those staff have all been excused. We're not utilizing those anymore. []

SENATOR GAY: Right. But we're still out actively looking for staff. []

RON STEGEMANN: Right. []

SENATOR GAY: You say we always are. []

RON STEGEMANN: Um-hum. []

SENATOR GAY: How do you go about that? Department of Administrative Services help you? I mean, did you hire headhunters to go look for people? How are we trying to fill those staff? []

RON STEGEMANN: Oh. We have contracts with four different radio stations. We continuously have radio spots that are on advertising for positions at BSDC, which includes the available \$3,500 incentive pay over the first two years and a starting salary

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that's above \$11.00 an hour. We use...pay for advertisement at some...mostly for some of the specialized positions. There is...DHHS has a Web site that has all available job listings on there. Many of the folks that come in and apply for positions, most of which when they tell us how did you...we ask the question, how did you first learn about this job. Typically, it's word of mouth, it's a friend works there, it's a cousin works there, my dad worked here for years. That's actually our number one contributor to folks coming in and doing an application. []

SENATOR GAY: Do you feel confident you're going to get these people hired? And I'm not talking...I know how hard it is to hire a psychologist, I...you don't have to (inaudible). []

RON STEGEMANN: Sure. []

SENATOR GAY: Do you feel confident you can get these hired? []

RON STEGEMANN: For the direct care positions? I feel very positive about the direction that we've gone in. I feel, while it is difficult for people that live in Beatrice and Gage County, some of the economic pressures that have happened recently, the reality of it is, and I've been in this business for about 20 years, when the economy as a whole suffers BSDC thrives in terms of being able to hire staff, bring people on board. So I think the outlook is very positive for us to be able to fill those positions. []

SENATOR GAY: Thank you. []

SENATOR LATHROP: Senator Adams. []

SENATOR ADAMS: Ron, if I may, I want to follow up on that same line of questioning. You, and reasonably so, you put a lot of stock in staffing to try to remediate these issues we have with CMS and DOJ. And I can understand that. And there's certainly spillover

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into some of these other areas of concern that we have. But recession aside, we're at a break point. What if we can't find these people? What if we find three months from now, six months from now we haven't filled these spots? []

RON STEGEMANN: We'll continue to... []

SENATOR ADAMS: What do we do? []

RON STEGEMANN: We will continue to reduce the census at the facility in order to make sure that we can provide adequate staffing at BSDC. []

SENATOR ADAMS: And would you tell me at this point again, I know we've talked about it before but it's been some months ago. What's the criteria for reducing that population? If we're going to reduce the population at Beatrice, I'm assuming, if I remember right there is some systematic way of doing that. There's an evaluation process of reducing that census. []

RON STEGEMANN: Relative it is. There is no one at BSDC who could not be served in the community given adequate community services. []

SENATOR ADAMS: Okay. Given adequate community services. []

RON STEGEMANN: Correct. []

SENATOR ADAMS: But if we're not comfortable there where does that leave us? []

RON STEGEMANN: Well, I guess, I was going towards your what's the criterion... []

SENATOR ADAMS: I understand. []

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RON STEGEMANN: ...piece of it. There's no assessment that you can do. There's no magic wand you can wave or anything else to say. Ron's ready, he's ready to go out to the community. The (inaudible) is, is the program ready for Ron. Are there adequate services across the board. Is there an occupational therapist there, if that's what Ron needs. Is there a physical therapist? Are there speech therapists? Is there a neurologist within 200 miles of where Ron is going? So that's the piece of it. It's not is Ron ready, it's is the program ready for Ron. []

SENATOR ADAMS: Okay. []

SENATOR LATHROP: Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. Hello, Ron. []

RON STEGEMANN: Hi. []

SENATOR WALLMAN: In this census thing we need this many more employees, is that for the current residents there or is that down to 200 or... []

RON STEGEMANN: If we would get our census to approximately 200 people, what I have determined as an appropriate level of direct care positions would be in the neighborhood of 225 to 235 staff. So we're not that far from there. []

SENATOR LATHROP: You have some questions? Go ahead. []

SENATOR GAY: Well, you say what you determine. But it makes no difference what you say determine. It's pretty much what the CMS says, doesn't it? []

RON STEGEMANN: My determination comes from work with the Liberty staff. And there is kind of a national standard that indicates that for each staff person you need on

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board you need approximately 1.8. So they multiply it by a factor of 1.8 to 2.0 in order to cover vacations, sick time and ongoing training. []

SENATOR GAY: That's where we think we need to be. []

RON STEGEMANN: Yes. []

SENATOR GAY: And we won't know that until we get the report back, correct? We're under report. []

RON STEGEMANN: Well, we'll know that when CMS comes and says you have adequate staffing, you've met the condition. []

SENATOR GAY: Yeah. And you feel confident that's the number and we're going to get there. []

RON STEGEMANN: Yes. If I wasn't confident in that I'm wasting my time. []

SENATOR LATHROP: That does give me some questions to follow up on. You were answering some questions and you said somebody I talked to before that was...at this job before me said I'll stay at the job as long as I have control over essentially how the place runs. []

RON STEGEMANN: Right. []

SENATOR LATHROP: And then you talked about, well, now it's a different world. And we have some people in Lincoln that are going to do some of the personnel things, for example, that was your testimony. []

RON STEGEMANN: Personnel, staff development, financing. []

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SENATOR LATHROP: Okay. So those things aside, it kind of is your thing to succeed at, isn't it? []

RON STEGEMANN: Yes. []

SENATOR LATHROP: And you've given us a list of outstanding positions. And I got an uncomfortable feeling when you said, well, if we can't fill them then we'll just downsize the place until the people that we have there equal enough people to provide for the residents that we're down to. Does that make sense? Maybe it's not a good question. You're...when you said, if I can't fill the positions then what we'll do is reduce the census at Beatrice until the people that are working there are enough to take care of the people that are left. []

RON STEGEMANN: That's the idea of the right-sizing. []

SENATOR LATHROP: The alternative to...see, that strikes me as a crummy reason to send people to the community-based programs. Okay? I'm going to share with you my feeling about that because last month we had hearings on the community-based programs. And I, personally, have taken phone calls from people that have horror stories about the community-based programs. I know that CMS is watching over Beatrice and they have rules and regulations. And when people go to the community-based programs we don't have any similar oversight. And I don't have a sense, after doing these hearings all summer long, that we have community-based programs that are ready for these people. Okay? And I'm also seeing that you've kind of hit a plateau in reducing the census, have you not. You started out with a goal, I think, of reducing 100 people. []

RON STEGEMANN: Um-hum. []

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SENATOR LATHROP: And you said you've reduced maybe three or four since we were down there in July. You kind of got rid of the low-hanging apples, if we can call them that, the cases that were easy to move into the community. And now we're down to how many more if you're going to meet your goal? Fifty? []

RON STEGEMANN: 56. []

SENATOR LATHROP: Fifty-six more people, and you have just a couple months left. []

RON STEGEMANN: Right. []

SENATOR LATHROP: It's probably not going to happen, is it? []

RON STEGEMANN: Probably not. []

SENATOR LATHROP: And that tells me that we don't have the services in the community for the people that you need to have leave Beatrice to right-size it so that the staff that you're able to maintain there is adequate. Is that also true? []

RON STEGEMANN: I believe that's reasonable. []

SENATOR LATHROP: So now there's two ways to look at this. We can look at it as a right-sizing issue, which would be okay if we had the community-based programs and the oversight and regulation and the things we need in place to make that happen or we can look at it as what do we got to do to get the personnel there. And what's been frustrating for me, Ron, is that when we talk about Beatrice and we say, okay, it's Beatrice, remember we can't get a lot of people to move to Beatrice or it's not that easy, Senator Lathrop, to get a physical therapist down to Beatrice because they'd rather work someplace else. We don't have an alternative, it seems to me, because right-sizing has hit its plateau. We've gotten rid of and we've moved people out of

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Beatrice to the point where the community-based programs aren't available for the people that you need to move out to get to right-size. And the only alternative is to work at the personnel issue and say, we need to tackle it. So here's the question, I think, that we're all here to find the answer to, what's it going to take, because the answer, it's in Beatrice, Senator, and it's hard to find people for Beatrice, doesn't work because it's the only alternative left or we need to hurry up and get some regulations and some oversight and some community-based programs that aren't in place. Right? []

RON STEGEMANN: And the answer is it takes more money. []

SENATOR LATHROP: Okay. You said you asked for \$5 million more. Does that get it done for a two year period? Does that get it done? []

RON STEGEMANN: I can't tell you exactly.

SENATOR LATHROP: You are the CEO of the Beatrice Development Center. You are in charge of running it--and I'm not trying to be critical with you. I'm not trying to be critical with you, but we are...we are, as a committee--and I'm not just speaking for myself; I'm speaking for everyone up here I think, it is frustrating because we get, we'll we could right-size, we're going to right-size but we don't have the community services. And then we say, what do you need? And we hear, well, it's a tough place to hire. And our answer is, we're going to lose \$28.5 million of funding at Beatrice. We are going to lose \$28.5 million worth of funding, and is that because we're trying to save 50,000 bucks? How much do you need to...how much money is it going to take so that we have the staff so that we satisfy CMS, satisfy the Department of Justice, and meet the recommendations of Liberty, who we paid \$1.5 million to for a consulting fee?

RON STEGEMANN: I think that's a fair question but I can't give you an exact answer.

SENATOR LATHROP: You have looked at the number of positions and you know what

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the pay is for each of them, and you know what the hours would be. Have you added it all up?

RON STEGEMANN: I know what the average pay is across an area. I can't tell you specifically what an individual person would come to Beatrice for. We still have to find the person.

SENATOR LATHROP: Okay. And I'm not scolding me, believe me. It's my frustration that you're hearing. My concern is that we can't wait to fill those positions. When CMS last came through--we talked to them yesterday and I don't think they think we're putting in the effort that we need to, to make things right down there and to meet the conditions of participation. That's my take. I think that's a view shared by the people that are up here with me. And I would sure hate to lose the \$28 million--and we may lose it anyway--but I'd sure hate to lose it because we didn't say, let's make an appropriation to get the professionals--and I'm talking about money. And there are people down there that deserve to have the proper care. They deserve to see the neurologist, they deserve to see the psychiatrist. I mean, that's why they're there. So do you have any...? Who do I talk to? Is it John Wyvill? Is it Chris Peterson? Who is going to give me the answer on what it's going to take?

RON STEGEMANN: I don't have the answer. Perhaps Dr. Wyvill does.

SENATOR LATHROP: Okay. That may be fair.

SENATOR GAY: I've got a question.

SENATOR LATHROP: Okay. Senator Gay.

SENATOR GAY: I guess, Ron, I asked you before and I'm not so sure is...here's the deal. What obstacles stand in the way of hiring these people? Is it...? And I'm not just

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saying throwing money at the problem, but sometimes maybe money is...you said that; you said that yourself. What's it going to take? It's going to take some money. No one wants to just throw money at a problem. But I guess you're working one way around the hiring by doing contracts. You're doing contracts. You talked about the speech pathologist I think it was. So you're being creative on certain other ways. But I guess you've been there 19 years and you said, well, we've always been short. And maybe what you're saying is, well, we may not get this done. It's a lot of people to hire. But I guess what we're looking for is, who do we ask and how do we get this done? Is that what you're saying is that you can't answer that question? You don't know.

RON STEGEMANN: I can't tell you exactly what it's going to cost to get that done, to get those people in those positions.

SENATOR GAY: Forget that then. How do we get it done? How do you get the staff, first of all? Because I think...I think, and I'm just, you know, what I'm picking up...

RON STEGEMANN: You go to organizations like Liberty, you go to organizations like Guardian, and you tell them I need two physical therapists here Monday and they tell you what it costs.

SENATOR GAY: And we can't do that forever, obviously, but it would solve an immediate problem but not our long-term problem, correct?

RON STEGEMANN: We've done that. We have contracts in place, and hopefully we will have a speech therapist there, come Monday.

SENATOR GAY: Right, in one position. But long-term, you can't go and just...no business can run that way, and we certainly don't want to run that way where we're getting...we're running it on temps is what you're telling me.

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RON STEGEMANN: Right.

SENATOR GAY: So, longer-term, how long do you think it would take to hire these people? I mean...

RON STEGEMANN: We have to look at the pay structure that exists within the personnel systems, and we've done that with developmental technician positions, we've done that with some of our management positions. We did the five-state survey and we came up with equitable pay for those positions. I don't believe we've done that in the speciality positions, in the therapies and physicians, psychology, and in all those positions. I don't remember them getting a raise out of the last group.

SENATOR GAY: Okay. And that's some...but equitable pay then, we're at an equitable pay issue now. You think you're at that number. And if you're at that number then we would be hiring these people...just because you're equitable pay, I mean, that still doesn't mean they're going to come flocking to your doors. That's a tough job.

RON STEGEMANN: Because we're still in Beatrice.

SENATOR GAY: Okay, we're going there again, and plus it's a very difficult job. I mean, we all recognize that fact. It's a difficult job.

RON STEGEMANN: One of the things I will say about Beatrice though, and I say we're in Beatrice and for some people that's not a very attractive place, but the reality of it is with the three administrative positions I've been able to bring on board, they want Beatrice. They're coming out of large cities in Ohio and Florida, and they want to go to a smaller setting like Beatrice, so it's not that Beatrice...I love Beatrice. I've lived in southeast Nebraska all my life, I think it's great, so it's not unattractive to everyone. But to many people that can make great amounts of money--psychiatry, neurology--it's not as attractive financially.

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SENATOR GAY: Yes, very difficult. And I agree with that. I think everyone can agree on that because we're doing all we can do to try to train people. It's the line person that you need, to me. You're still...those are the biggest numbers when you read all those jobs that were open, those positions that were open.

RON STEGEMANN: Yes.

SENATOR GAY: And maybe we need to do something other than radio advertising or maybe we need to go look outstate and try to recruit people or...I don't know what the answer is and I guess that's what we're looking for.

RON STEGEMANN: I think some of it we're doing now. Because, as I stated, one of the biggest morale issues that we have is the fact that we are holding people for mandatory overtime. We're down to 28 hours for the last reported pay period. That's word-of-mouth. That goes from our employees back to people that they know within Beatrice and the Gage County area. We believe morale has increased at BSDC. When that increases on campus it gets converted to morale within the city of Beatrice itself. We know we had a period of time when we were bad-mouthing ourselves as much as the papers were. I don't believe that exists anymore. I believe we're turning that around. I believe that our staff are recommending BSDC as the place to work, and that's probably the biggest draw--we know that because they tell us that--to getting new frontline staff and to work at BSDC. And then it's my job, it's the administration's job, it's everyone's job within the organization to make that a place that people want to stay at and be a part of. And moving BSDC forward and making it successful and getting us through all of what we're in now, including--not that it's terribly bad--but my involvement with this group goes a measure towards making it a better place to work.

SENATOR GAY: So you answered the question. You're making strides is what you're saying and that's how you did it. And do you think that will continue on...

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RON STEGEMANN: I believe so, yes.

SENATOR GAY: ...to make it a better place, to I want to go work there. That's a good answer.

RON STEGEMANN: That's the biggest thing that's going to get frontline staff there.

SENATOR GAY: Okay. Thank you.

SENATOR LATHROP: I think that's it, Ron. I know it hasn't always been comfortable but you have educated this commission, you have given us information that we have asked for, and we know you are down there doing the best with what you've got and we appreciate that. So thank you for your testimony again today, and we'll have you step aside and make room for John Wyvill.

RON STEGEMANN: All right. Thanks to each of you.

SENATOR LATHROP: Thanks.

SENATOR GAY: Thanks, Ron.

JOHN WYVILL: Good afternoon, Senator Lathrop, members of the committee. My name is John Wyvill, W-y-v-i-l-l. I'm the director of the Division of Developmental Disabilities and I'm the one responsible and accountable for BSDC and DD services in the state of Nebraska. And there's a couple of items if I may, can address based on questions that have been asked for the committee, addressing (inaudible). For your information, we have been consistently working and looking for placement of folks outside of BSDC for some time now, part of our right-sizing initiative. We are currently what we do with Service Coordination and with Sue Spitsler, our transition specialist at BSDC, and with

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help from our community staff in Lincoln, and we work with Service Coordination twice a week to go over a matrix of clients that are being considered for community placement. Those individuals roughly equate to a number of 50. Part of that process that we're also working for is that we have identified 92 individuals that do not have a behavioral management plan or (a) on psychological or psychotic medications that we have identified that would be appropriate for community placement right now, but for guardian opposition. Twenty of them can move into the community today if we did not have guardian opposition. The others have smaller obstacles or barriers relating to health or accessibility that can be easily worked with the provider and take a little bit longer transitioning. As a general rule, if a guardian or a loved one expresses their intent or interest to go into a nursing facility, that can be done fairly quickly. If it is a community placement, it takes up to a month or a month and a half or two months working with the provider to ensure that there's a safe and appropriate placement into the facility. The second, the issue brought up about the budget for recruitment and retention, that is in the...the budget for that is outlined, I believe, in the six-point plan. That is how we are allocating the money and that will be the best way to describe some of the efforts as was gone into hiring of the temporary agency folks and hiring them, and made a decision to allocate additional resources, so we don't want to create the mistaken impression to the committee that we have used the vast majority of the money for temporary agency folks. I think the guideline for that, if you have any questions, is in our plan as to how we use to spend the money. And we do want to say right now as a result of the action by the Legislature and the Governor in this particular thing has yielded some wonderful benefits and opportunities for us. We had previously provided, I think last week, a document of a letter transmitted, dated October 8, that we refer to that announces a lot of the changes that we have made doing staffing. One of the things that's very significant is that we have an orientation facilitator that's on board that is helping with orientation, and a meeting with, I believe with Senator Harms, our staff had indicated that that individual alone was responsible for retaining eight direct care staff that were contemplating quitting during the orientation process, and they were able to intervene. So also in addition we are working very closely and hope to have an

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announcement soon on four mentors that will be assigned responsibility for the new direct care staff, working side-by-side with them as well as providing assistance. That is a direct benefit of the recruitment and retention plan, and I just wanted to share that success with you. I know the committee has a variety of questions that they want an ask me so I think I will stop right here and let you get to the heart of the matter.

SENATOR LATHROP: John, thanks for coming. You have been at almost every single meeting, and we appreciate your continued interest and the efforts that you've put into this. We'll see if folks have questions for you, and we'll start with Senator Harms.

SENATOR HARMS: John, you were present for awhile at that meeting that we had with the staff development people. Have you looked at and have you reviewed the actual material that they have in their training program for the staff? I'm coming back to what CMS had mentioned to us yesterday. It bothers me just a little bit that we might be using material that's antiquated and not appropriate today, and I just wondered where that check and balance is and who reviews that so that it's appropriate.

JOHN WYVILL: Senator, I have reviewed a lot of documents. I know at one point that I have reviewed the training, and one of the things that Liberty and others have said is that we need to have training consistent with best practices of ICF/MRs across the country. And I believe in the materials that we have given we have individuals that are coming on board that will be providing that training, if not already, also in areas. I think you'll see in there Michael Small (phonetic) is going to be providing People First-centered training. We also have other just-in-time training. In addition, we also...my staff had shared with me your thoughts about some of the possible other training, and we're very intrigued about that and about that possibility.

SENATOR HARMS: I can tell you if you can get it done it will make a difference for you and also make a difference for Beatrice, and may even other parts of government.

There's some great opportunities there. John, I wanted to ask you about Liberty and the

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\$1.2 million or whatever the amount is. Where did that money come from?

JOHN WYVILL: I believe it came from federal "turn back" money.

SENATOR HARMS: Okay. So it was money that we didn't...explain to me how that federal "turn back" money works.

JOHN WYVILL: I believe that we have money that we have available that the federal government gives us back in reimbursements, and then we use that money to fund Liberty Healthcare.

SENATOR HARMS: Okay. In regard to the budget, Ron had mentioned that \$2.5 million for each year which is \$5 million total. Do you really think that's adequate to...? With the issues that you see at Beatrice, do you really believe that \$5 million will really make that much of a difference to help you? I mean, what's it going to take to address the issue, because when I look at that and I look at your waiting list, look at all the other kinds of things that are there, it doesn't look like to me that \$5 million is appropriate.

JOHN WYVILL: Senator, based on the information we have now I definitely think that it's adequate to address the challenges at BSDC. I think the challenges now at BSDC are not a resource issue, however we could eventually have to reevaluate based on whatever recommendations that this committee gives us to consider for other ideas that we have not thought of.

SENATOR HARMS: So based on the best information you have, could you share that with me? What is that?

JOHN WYVILL: That is, I believe, on...I don't know the exact (inaudible) and we can certainly share that budget with you.

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SENATOR HARMS: You're talking about the budget of \$5 million. Based on your judgment of the best information you have, that's adequate, so I'm trying to find out what is that best information that makes it adequate.

JOHN WYVILL: Okay. That is based on our consultation with BSDC staff, with our attorneys, with our budget office and analysts of the information that also takes into account a variety of different factors so they can give us the dollar amount.

SENATOR HARMS: John, in regard to the community-based programs that we have--I think probably the majority of us here probably have a concern about that--what's the savings by taking one of the clients and moving them from Beatrice to a community-based program? What is the actual savings to the state or what's the difference in the transfer of dollars? What is that total up to, do you know? []

JOHN WYVILL: I'd have to look that up. I think I provided that to the committee previously and I don't want to hedge on that, but there is a significant savings if someone goes into the community, because I think BSDC with all the costs associated per client is significantly higher than one would be in the community-based setting or one in a nursing facility.

SENATOR HARMS: So we wouldn't be moving them to save money, would we?

JOHN WYVILL: That's not the issue you've heard. You've heard the debate about appropriate community settings and what would be the best interests of the clients and the availability of choice. One of the things about the system of care for developmental disabilities is outlined and it's made it very clear among everyone that we've heard that BSDC has a place in the system of care in order to effectively and best able to do its job, and we feel that there are individuals out there that have opportunities to do even better in the community. We respect the choice to make that decision. One of the other issues here that we have slowly and steadily signaled a shift in our philosophy, is the

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philosophy is they're talking about the community placement in terms of Homestead more so than the necessity for our staff because we feel very comfortable (inaudible) how we're progressing and implementing our plan, and our plan is just very simple. It's skilled leadership, establishing an effective organizational structure, continued right-sizing the facility, and recruitment and retention and training of staff, and successful community placement.

SENATOR HARMS: In regard to the community-based program...no, I'm going to leave that alone, John, for right now, so I'm...

SENATOR LATHROP: Greg. Do you have any questions you want to ask before you leave?

SENATOR ADAMS: I'm going to have to leave here in a minute so if I could...

SENATOR LATHROP: Right. Go ahead.

SENATOR ADAMS: John, correct me if I'm wrong. A moment ago did I hear you say that you believed the situation specifically at Beatrice is a resource issue?

JOHN WYVILL: It is not a resource issue. It's not a money issue in my opinion.

SENATOR ADAMS: Is not a resource issue. Okay. So let me ask you the obvious then. I asked the same thing of Ron. If it's not a resource issue, how did we get to this point? What's the issue?

JOHN WYVILL: I think--first of all, I'm glad you asked that question because obviously that is the question for everybody on the committee--I think based on my review and based on my opinion I think there are several contributing factors. The problems at BSDC were long in the making and to get to the point that we got where the 12 federal

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surveyors showed up on our doorstep in September 2006, and I think there are several things that have contributed to it. I think first was an organizational change. I understand that in about 1997 BSDC was under DPI, I think was the Division of Public Institutions, and from what I understand from talking to a variety of people that there was a lot of loss of brain trusts or whatever when they had turnover during that organization--not a criticism of what the decisions back then were made (inaudible) I think that was one contributing factor. I think another contributing factor was after we heard this Horacek v. Exon lawsuit. I think you've heard Bruce Mason come before this body and talk about that when he was practicing I think in 1972 or something like that where he was talking about the facility was over 1,000 individuals, and after it reached a certain point in reducing the census it kind of got stuck in terms of having no clear purpose or no clear goals and objectives, and I think that contributed to it. I think also some of the other factors I think was the organizational structure. I think it was the Department of Services at one point, in which one director, I think someone like me, would be responsible for children and family services, DD, veterans' home, and behavioral health, and I think that caused the director to be in a crisis management mode. I think obviously if you look at the survey results, if you look back from 1999 on, there's been some consistent challenges at the facility. It appears to be, in talking to staff, it's unclear as to whether or not the higher-ups knew about it because there wasn't a mandating reporting of those kind of information, so some of the problems that we're experiencing in 2006 were there in the survey findings in 1999 and '98. And then also, as expressed by staff--not as an excuse--is that some of the expectations of CMS over the years may have changed, and I say that just that a lot of it can be subjective. That's not a major contributing factor but that is one element that has to be taken into effect because the question comes is why weren't we hearing about this before 2006. And that, you know, you kind of wonder is everybody correct or what's going on. So I think all those, I think, played significant factors. Also with the stagnation at the facility, the facility didn't keep up with the contemporary practices of ICF/MRs and kind of lost its edge. But I do want to share one thing while we're talking about the problems that I've already mentioned, what we're doing to fix it, that we have, that you have seen here that we have extraordinary

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individuals doing extraordinary things down at the facility. We have people that are there 24/7. We have individuals on weekends and holidays, and when you're at home for Thanksgiving or whatever you're doing Thanksgiving, that we have our direct care staff and our staff working side-by-side with the clients. The client, the staff, had put up with being suspended for allegations or false allegations, and time and time they've come back, and they don't quit, they don't give up despite the negative publicity and I think you've mentioned with that, and they still have that eagerness to learn, eagerness to incorporate new ideas and new ways. And that's what our job is to do, is to help fix the problems. And part of that problem in the past was a disconnect between management and direct care staff. And I think all those factors together contributed to where we are, Senator, and we have and we believe that we have a plan that is fixing and addressing those problems, and we certainly welcome any additional suggestions. I know I can speak for Ron and Chris Peterson. We take no pride of authorship, that if someone has a good idea, the committee has a good idea, well, you know, if we haven't thought about it we certainly want to embrace it. It might be embarrassing that we didn't think about it, because that's what we're paid to do, but at least it's said, give it to us and then we'll see what we can do to go from there. So hopefully in a nutshell that outlines what I think got us where we have.

SENATOR ADAMS: Thank you. That's very forthright. One of the things, and you've been here, John, to hear this, that we've heard fairly consistently from the guardians and the parents of some of the clients at Beatrice is that there was a time in the 1990s when we had a top-of-the-line facility, a cutting-edge facility, a model, and we've lost that. And maybe your description explains potentially why we have lost that and we are at the point where we are now. Appreciate that.

JOHN WYVILL: And also we don't want to confuse two things so that our lawyer doesn't kick me in the chin under the table here, is I'd point out is that when we are outlining the things that we're doing, is that our goal is not just a minimum condition to participation, is to be the best facility in the state of Nebraska and return it back to where it was, and

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that is our goal. And that's why we have made a concerted effort to get skilled leadership there to revamp an organizational structure, bring in the experts that tell us what we need to do, and continue to do what we're doing in addressing recruitment and retention and training staff. And we've gotten a lot of input and suggestions from a lot of different folks, and I can't think of anyone in this room that wants us to fail.

SENATOR ADAMS: That's right.

SENATOR LATHROP: Senator Wallman.

SENATOR WALLMAN: Thank you, Senator Lathrop. Thank you. I too agree. I'm thankful you're on board; and direct care staff, I'm proud of them probably 99.9 percent; and also the parents' group. As we get down here, is you've got empty space at BSDC buildings as we've downsized?

JOHN WYVILL: We will have vacant space, Senator. We also have as part of our long-range plan, for example, the administration building I think has some foundation issues with it and we anticipate that we will be moving that to the what's referred to as the hospital annex. And I think that is going to be well-received because I think in addition that puts a lot of our administrative staff right in the middle of our direct care staff and interaction with our staff, and I think also helps address one of the feelings from direct care staff that sometimes the management is not there to support them.

SENATOR WALLMAN: I think that's good too. Is there any other buildings empty or just that one or...?

JOHN WYVILL: I think...I'll have to check with Ron. I'm drawing a blank right now. But we just recently, I think earlier this week, were closing a building to renovate it for making it more accessible to move a different client population into one of the cottages. I think the role is to get out of the dormitory-style housing into the more

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community-friendly cottages or living spaces to replicate living in a community, and remove that stigma of an institution not just for the sake of that but to give the clients the opportunity to have meaningful days and have the fullest opportunity to them.

SENATOR WALLMAN: Thank you.

SENATOR LATHROP: Senator Harms. (Laugh) John. It's getting late.

SENATOR HARMS: Yeah, it is getting late. Thank you, Senator Lathrop. John, just a question I wanted to ask you about the waiting list. Yesterday we had testimony here about the waiting list. It came up and it was pretty evident...I left here yesterday almost depressed and with a heavy heart, listening to the parents and guardians and loved ones, a son or daughter who they have that's on the waiting list. And they're in the aging process and they can see that in time if something happens to them there may not be anyone here to really help take care of that son or daughter. And the waiting list is a big issue with a lot of people. You have a lot of people on the waiting list. And they also brought forth information that we have people, parents who are leaving Nebraska because they don't see any hope of services for their son or daughter in the very near future. How do we address that issue, John? I know it's expensive, but, you know, somehow we're going to have to come to grips with that issue.

JOHN WYVILL: Well, you know, obviously any director would love to have additional resources and additional funds. One of the things that you'll find out is that we have the legislative resolution, LR156, which Mary Gordon is assisting on, to do recommendations, as well as give you some of the information that can assess the true extent and scope of those people that are waiting for services.

SENATOR HARMS: So what is your estimate of the cost to address that issue?

JOHN WYVILL: I think right now, and Senator Lathrop has asked me to update and give

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you the most updated information, so obviously we'll supplement that to give you the most accurate information, but I think right now there's about roughly it might be 1,900 people waiting for services that might have over 2,400 requests for different services. That might be respite day services or habilitation and that. That number that we have given a little bit earlier, right now best projection is \$80 million, and that's not factoring in any...that's based on the requests and based on the their date of need of services, and that doesn't account for other individuals that were requesting services right now in anticipation of future time. And I think given that amount total, I think you're looking at over \$136 million.

SENATOR LATHROP: Senator Stuthman.

SENATOR STUTHMAN: Thank you, Senator Lathrop. Thank you, John, for your information. A concern that I have is when CMS found areas that they were not satisfied with, have they given or indicated anything as to what it really takes to make them satisfied? I mean, you have your plan to fix the problem. Is your plan going to be satisfactory to meet CMS's anticipation?

JOHN WYVILL: Senator, we think so, but one of the challenges that we have is--is not a criticism of CMS, it's just the way that they're structured--is that they're not structured that they can also provide us technical assistance, and we can't go to them and say, will this work, will this work, will this work. They say, here's the problem, here's the issue, you need to figure out how to fix it. In working in other branches of state government where I've worked under the Department of Education, they do afford technical assistance. So sometimes that creates some of the challenges, is how do we know that we're addressing it to meet their expectations and needs. And ultimately they're the ones that make the decision, and it's not meant to be a criticism, it's just that's just the way it is.

SENATOR STUTHMAN: That is the concern of mine, because, you know, they say,

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well, this practice is not acceptable, but that's the end of the conversation. You say, well, we're going to fix it in this way, but that's not acceptable either, and then you...

JOHN WYVILL: Well, they may not say it's not acceptable or they may say, yeah, it's acceptable or things like that, and that's why sometimes we have to resort to nationally recognized experts to assist us to make sure, based on that, to make sure that we're meeting it. And I am very confident we've been very fortunate and blessed to have Liberty Healthcare. We currently have a person that's helping us with that quality assurance with Liberty Healthcare, that's working with us, and we have our attorney, Tom York and Jodi Fenner, and doing our best.

SENATOR STUTHMAN: And there's still no guarantee that's it's going to be acceptable.

JOHN WYVILL: No. It's their call, not ours, and they've made that clear many times, and that's just the way it is in a regulatory environment. I'm not criticizing it. It is what it is.

SENATOR STUTHMAN: Okay. Thank you.

SENATOR LATHROP: Senator Gay.

SENATOR GAY: John, when you did you start here?

JOHN WYVILL: September 17, 2007, and I think in my first month on the job I think federal surveyors were at BSDC I think 17 out of 21 days. []

SENATOR GAY: Is that right? Yeah, so welcome to Nebraska. (Laugh) []

JOHN WYVILL: And for the record, I am still in the dog house because I had to be at BSDC on my wife's fortieth birthday dealing with the Department of Justice. (Laughter) And hopefully I'll be able to make it up to her this year. []

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SENATOR GAY: Well, I guess looking at this, I remembered you've been working on this and now we have a committee looking into it. Senator Stuthman and I have been hearing about these problems for awhile. At some point we are going to correct...we will correct this Beatrice problem. I mean, we'll get it done, do what needs to be done. Senator Harms talked about long-term, we talked about waiting lists and some of these things. I guess, real quick, what's your vision of...? And then we...well, where I'm going, we talk about...Senator Stuthman just asked you, well, how can we satisfy CMS requirements, and you said, well, we don't know, we don't know. But I think what they're saying is be proactive, not reactive. And we're looking for a fixed list, a punch list, saying if I do these things I'm in the clear. Well, that's fine, you're done for now. But we talked...Senator Adams talked about how did we get in this mess. And over the course of years we've just been letting things slide it kind of sounds like. I'm not pointing fingers at anybody, but probably everybody, you know. You had talked about how the changes of which department it was in and all these things. In the future though, how do make sure--as a committee we were struggling with this--how do we make sure that things are being done and things are being tended to? What's your vision of once you get past this crisis, what's your vision of the DD community in Nebraska? Where do you want to go in...? []

JOHN WYVILL: Okay. Well, obviously, Senator, first we want to remove the cloud of uncertainty hanging over all of us about the federal funding relating to CMS. But I want to first and foremost let you know, members of the committee and everyone else here, that we take that very, very seriously, and I think we're doing our very best. But I think the thing I'm reminded in preparing for this hearing, there is an old proverb out there that says, remember history, lose an eye; forget history, lose both eyes. And I think it's very critical that we have to be, first of all, aware of the history of how we've gotten where we are, and then where we'll go. The vision for community-based services, I see it first of all is successful implementation of the DOJ agreement, successfully navigate the minefield post with BSDC relating to federal funding, and then establish and reestablish BSDC as

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a premier facility in providing care for those with developmental disabilities, specifically in the area also of ITS, which is intensive treatment services. If you talk to any provider, and they will say if they have anything they want, obviously besides more money for their rate, which is, by the way, included in our budget request. We have a 2 percent budget increase and I think we're the only division that has a 2 percent increase. I think everyone else has 1 percent rate increase--is to make sure that we have ITS, expand their capacity for intensive treatment services, make sure that we increase and enhance our oversight responsibilities on the community-based side, which we are doing by...we are...I had pulled back the 404 reg, which you may have heard about, that I think were in hearings in September 2006, to reevaluate those specifically based on the lessons learned from the Autism Center of Nebraska thing, and then we are evaluating how we can improve our oversight either by contract management or enhancing staffing to make sure that, as a community provider, that folks in the community feel that they have the same level of scrutiny. I think to give you a picture of BSDC, in a typical week we could have someone from Public Health, from Regulation and Licensure there on a complaint, and we have Nebraska Advocacy Services, we have the independent expert, we have our own (inaudible), we may have Senator Wallman there on a regular basis. So there are times where people are tripping over themselves, and that's a security and comfort that BSDC has. And all of this is to say is that people are saying if they feel that the clients are safe here, they want that kind of assurance and safety in community-based programs then. We're exploring and evaluating ideas about how we can make the general public or the Legislature aware of incidents like in BSDC, for example nowadays at BSDC if something bad has happened or something newsworthy, that's in the paper. You don't hear anything about that with the community providers. That's a division that we want to do, and we're also working on a couple things relating to expanding capacity. We're working with one provider to expand the capacity for at-risk clients at BSDC for community placement, and that could result in several individuals moving out of BSDC. In addition, we're exploring expanding some other programs through pilot programs. So I think we're constantly moving, constantly striving for excellence. So hopefully that gives you a little flavor of our vision for DD. []

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SENATOR GAY: That does. And, you know, I've said many times, I think we have some excellent people, and you stressed that and we all agree I'm sure that what goes on, there's some great employees down there working very hard and none of us are criticizing that fact. I'm just...it's...we kind of need to know, I think, that there is a vision and something beyond this, and we need that comfort to fix this problem and that you're going to move on down the road. So I feel fortunate to have you, so. But thanks for answering that question. []

JOHN WYVILL: Okay.

SENATOR LATHROP: John, I have a few questions. []

JOHN WYVILL: I knew it was coming.

SENATOR LATHROP: Well, I do want to...you made a remark and I want to comment on that, that you have extraordinary people at Beatrice. And, you know, there's a lot of people sitting behind you who are friends of Beatrice, who have family members in Beatrice, and they've all been up here and told us exactly what you've just said, which is there's a lot of great people working down there. And when we went to Beatrice, there were a lot of wonderful people, committed people to a challenging population, and couldn't agree more, and that's a credit to the community of Beatrice and to the organization. I also, for the benefit of the people who are here and who were not in Beatrice when we held hearings there, even the employees had good things to say about you.

JOHN WYVILL: That's kind of them.

SENATOR LATHROP: So that's been my experience in working with you, too, and so I don't want you to misinterpret my questions as a criticism, John, but I do want to ask

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you some questions about or talk about the CMS for a minute. When CMS...they're basically the agency that oversees what we do and are we doing the things the right way as long as we're getting Medicaid money or federal money. Is that basically true?

JOHN WYVILL: Yes. If you participate in their program you've got to play by their rules. []

SENATOR LATHROP: Okay. So if we want--and we do--we pay for about half of the cost of running Beatrice with federal dollars, and that's basically Medicaid money, and so CMS comes in and does surveys or inspections to make sure that we're following the rules. []

JOHN WYVILL: Very important and a critical part of this process. []

SENATOR LATHROP: Right. And since we're using and taking their money to help fund Beatrice, they dictate the rules. And the rules are pretty clear, are they not? []

JOHN WYVILL: Yes. []

SENATOR LATHROP: Okay. That's not a...it's not like we don't know what they are or they keep changing. There are...and the structure of the rules when you take federal money are these. You have conditions of participation and there are eight of those, am I right? []

JOHN WYVILL: That's correct. []

SENATOR LATHROP: And those are the overarching criteria for providing good care, providing a safe environment, having enough people there. They are the eight things that are the big-picture items, am I right? []

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JOHN WYVILL: Very similar to like, for example, the federal rules of criminal procedure and civil procedure, and the rules of evidence. Those are the rules. []

SENATOR LATHROP: They are the rules. And beneath those or perhaps in greater detail are a whole bunch of standards, am I right? []

JOHN WYVILL: Standards and indicators. []

SENATOR LATHROP: Standards and indicators. So if you violate something, some of those standards, and somebody is in immediate jeopardy, we can find ourselves out of compliance with the conditions of participation. []

JOHN WYVILL: Yes. There is a possibility if...there is a determination by a CMS surveyor on site that there's an immediate jeopardy, that could put us out of condition for whatever it is. In addition, the governing body is out of condition. And then what we have to do is, in the terms of art and the CMS regulatory environment, is that we can give them what's called a letter of abatement, which is to say we may not necessarily agree with you but here's what we have done to address this issue. And then they can determine whether or not that condition has been abated, and I think you have 21 days, I think, in order to get that IJ, immediate jeopardy, abated. []

SENATOR LATHROP: Okay. So we can find ourselves in problems with those conditions of participation either by having an immediate jeopardy that rises to the level of violating a condition of participation or we can also get there by a thousand small cuts, can't we, by violating several smaller standards to the point where they just say, you know what, you're not meeting a condition of participation. []

JOHN WYVILL: That's correct. []

SENATOR LATHROP: And those are thing like governing body and management;

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another one is client protections; another is facility staffing; another is active treatment services; yet another is client behavior and facility practices; two more, healthcare services, and finally, dietetic services; and then there's an eighth, is there not. []

JOHN WYVILL: Yes, there is. []

SENATOR LATHROP: So those are kind of things that they say: If you're not meeting those we're going to take you out of compliance; you don't fix it, and we're taking away your certification. []

JOHN WYVILL: That's correct. []

SENATOR LATHROP: Now when we met with CMS yesterday, they gave us a sheet and I had the page put a copy of it in front of you, which is kind of their summary of how things have gone since September 2006. Can you see that? []

JOHN WYVILL: Yes.

SENATOR LATHROP: And in the column on the right side it has conditions of participation which have not been met. Do you see that?

JOHN WYVILL: Um-hum.

SENATOR LATHROP: And they go through each date they were here either for a survey or a follow-up or an incident investigation, and they say when they left how many of the eight conditions of participation had not been met when they left. Is that right?

JOHN WYVILL: Um-hum.

SENATOR LATHROP: And that's essentially...not fixing those is essentially what got us

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decertified by CMS back in December. Am I right about that date? Is it December or January?

JOHN WYVILL: We got...I think or recently we got our citations in September 2006, and then in April that's when we should have gotten our termination letter but we didn't because it's my understanding they liked the progress that was made from September to April 2007. And I think there was only one condition of participation out, but because there was client protection, that automatically knocks out governing body. And so you're talking about being out seven of eight, all the way to one. So they liked what they received. And then in October they came back and then said, no, you didn't make it. And we had them...they have commented on both times, especially when I was there in October, a comment in there, we made significant improvement but they felt that it didn't meet the conditions of participation, and then that's when we got our technical termination letter. And when they came back in March 2008, '08 I think, that's when they said, nope, you're still out and we're going forward with the termination. In the meantime we had already filed our appeal and appealing their determination from October, saying that we disagreed and we have alleged substantial compliance, and we felt even though we had...notwithstanding their opinion, we felt that we were in compliance. []

SENATOR LATHROP: Okay. Well, I want to...I'm looking at their sheet, and you say we're down to one. And I'm looking at March 2008... []

JOHN WYVILL: No, that was back in April. I'm not...

SENATOR LATHROP: ...and they still have four conditions of participation that they say were out. We met with these folks yesterday. And for the benefit of people who haven't been in the middle of all of what you and I have been involved in, the agreement with CMS is they come in because there's some outstanding litigation. They come and have a private conversation with or an unrecorded conversation with members of the commission. We did that yesterday. And we have an appeal pending, and after they left

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I don't have a lot of confidence that we're going to prevail in that appeal. Okay? And I'm not...I have a lot of concern about that, because as I listened to and as I look at the conditions of participation, almost all of them--and maybe you can agree with me on this one, John--almost all of them go back to our personnel. I mean, if you look at whether we're providing protections and safety, or governing body and management, it ultimately comes back to whether we've got the right people and enough of them there. Would you agree with that, that most of our problems with our conditions of participation go back to personnel issues and staffing issues?

JOHN WYVILL: I think the challenges that we have involve staffing and active treatment. []

SENATOR LATHROP: We have an appeal pending, and I...you talk about--and maybe your counsel can stop you, I don't want to try to jeopardize our appeal whatsoever--but basically that process is, we kind of submit things and say if we've given a chance to present testimony we'll say these things and we think we are in substantial compliance. []

JOHN WYVILL: We believe we're in substantial compliance and we have outlined in this book that we have provided you that we made even significant enhancements above and beyond what's required by the minimum requirements imposed by CMS. []

SENATOR LATHROP: Okay. But every time we don't fill positions, if we don't have a psychiatrist or a neurologist or we don't have enough of those people, then we're not providing all of the cares that we need to and that places us in problems with our compliance. And so we have facility staffing problems, which is a condition of participation, and then ultimately it kind of rolls up into a governing body management issue, as well, am I right? []

JOHN WYVILL: Correct. []

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SENATOR LATHROP: So with \$28 million at stake, and--and I feel kind of crumbly talking about in terms of money because there are people whose care and whose level of care we're talking about--but just for the moment we talk about the funding. We have openings that have remained open, that go right to the very things that CMS has been critical of. And it's like I feel like we're being penny-wise and pound-foolish. What do we have to do to get these positions filled so we can provide the care and avoid losing the \$28 million? []

JOHN WYVILL: Okay. Senator, there are a couple things that we feel that are going on to give the proper context. When...and the purpose of the appeal is that in October when they showed up there were 332 clients at the facility... []

SENATOR LATHROP: What year? October of what year, John?

JOHN WYVILL: October of '07. Three hundred and thirty-two as of October 1. As of October 1--I don't know what the census was when they came and visited in October--but 332. October 1 of this year we were 256. So we have made significant changes when we made a change in philosophy to right-size the facility in December, so...and we have, since September...I mean since October of last year, and we've had the census of the facility dropping. And we have, based on here, the level of our staff enhancing. We also have professional staff enhancing. We have challenges in two different areas that we feel that we have addressed. Number one is in the area of direct care, with the help from the Legislature about recruitment and retention, and then we also have the professional staff. If we cannot get professional staff to work for us, we contract with them. It's that simple. In the market out there we have seen, with the professional staff, that the speech therapists, the occupational therapists, and others, it is a buyer's market for them. They can pick and choose. So when they're in that situation, then we contract with them if they're not willing to work for us. That's just the environment. There are some individuals that are making too much money in the private

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sector or don't want to dabble in this. But the very risk also in the professional sector, which is a challenge that we're addressing, is that individuals with professional licenses are unwilling to put their license at risk to work with the DD population, because if they get an abuse and neglect allegation against them, their license and they're hearing from Public Health, because then that's a mandated reporting requirement and then that creates a challenge for them. So we have individuals, globally, that would say, yeah, I'd love to help you out but I'm not going there. But don't mistake that, the challenges is they're talking about this is the gold standard that we're going and shooting for is we want to be the best facility. And we feel that even now, even (inaudible) and we've made our case even better with all the enhancements that we've made since December, saying that. But ultimately it is the decision for the administrative law judge, it's a decision for CMS that we meet their needs. And we have alleged compliance and we think we are in compliance and we're moving along, and we think...

SENATOR LATHROP: John, I believe that you are shooting at the gold standard, okay. I mean you and I have worked together on this since last spring. I believe you're shooting at the gold standard. Has Ron Stegemann made a recommendation to you about how much more money he needs compared to last year to make this happen? []

JOHN WYVILL: He has all the resources available that he needs. []

SENATOR LATHROP: My question though, John, was whether he asked you, as...you're the person he would report to, am I right? []

JOHN WYVILL: That's correct.

SENATOR LATHROP: Has he asked you for a particular dollar amount to add to his budget so that he can put on the people, by whatever means, contract or by retaining them as employees, has he asked you for a particular amount of money?

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JOHN WYVILL: Not specifically, but I asked him, is there any additional funds or resources? And he said he's got it all. []

SENATOR LATHROP: So he doesn't need what? He was here a little bit ago and said... []

JOHN WYVILL: Money is not an object. We have the resources. []

SENATOR LATHROP: So we have appropriated and we are asking for enough money to fill these positions. []

JOHN WYVILL: I believe so, if you approve our budget request. []

SENATOR LATHROP: Pardon me?

JOHN WYVILL: If you approve our budget request.

SENATOR LATHROP: You mean, the Legislature?

JOHN WYVILL: If the Legislature approves our budget request.

SENATOR LATHROP: Okay. Okay. So you think with whatever you've requested you can fill all the vacancies that Ron just went through with us? []

JOHN WYVILL: We'll fill the positions that we feel that will be needed. We don't want to get hung up and confused, even though we have vacant positions that doesn't necessarily mean those positions need to be filled, because we have an allotment, for example, that may be projecting facility staffing, for example, based on the first part of the biennium. And as the census goes down, if we don't need that, when you heard about the 100 that we were looking for, it's now down to...we're actively recruiting 27

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direct care staff. And what we will have here is very soon and we're also getting is that we have our direct care staff complaining now that they're losing their overtime, and which we think is a good complaint. []

SENATOR LATHROP: Well, so do I. So do I if that's going on, because that's a long ways from where we were a year ago. It sounds like we are...I want to make sure that we're talking about the same thing, because I asked if you were going to have the resources to fill these positions, and I think you answered my question a little bit differently than I asked it, and that was we'll have the ones that we think we need to fill. That's different than whether you're going to fill them all, am I right? []

JOHN WYVILL: That's correct. There may not be a need to, and that goes back to a question you had before, is the question if we go out and fill a whole bunch of positions and then our census goes down five or six more, as we project to do, we don't want to be in a position then of spending our time for recruitment, spending our time for training, and then have to say, oh, by the way, two months from now we're going to have to lay you off because we don't need you anymore. []

SENATOR LATHROP: And I couldn't agree that that would be a miserable personnel practice, and the state doesn't want to get involved in that. As you target what you think you're going to need as opposed to all of the vacancies that Ron told us about, what's the census at Beatrice that you think you'll be at? You're making an assumption about your census, am I right? []

JOHN WYVILL: That's correct. []

SENATOR LATHROP: Tell us what you believe your census will be when you calculate what your needs are going to be, as opposed to filling the vacancies that we just heard about.

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JOHN WYVILL: I think we constantly evaluate that on a monthly basis, and we're waiting right now for Dan Hyman, who is the head of Neighborhood Services, to finish his review and evaluation, and then I think we'll be meeting fairly shortly with him and Ron to discuss what the next steps are in terms of staffing. And I think as our census goes down, we're constantly reviewing and evaluating it, and right now evaluate that, as we are going down, that we'll be looking at other areas of non-direct care staff that we may not need.

SENATOR LATHROP: A minute ago you said that there are...you made the distinction between the openings that are there right now and what you expect to be your needs, and you said we're not going to try to fill all of the openings because we don't want to lay people off when we find out we didn't actually need them, so you must have some assumption about where you want to take the census at Beatrice. []

JOHN WYVILL: Well, our goal is 200 at the end of the year, Senator. []

SENATOR LATHROP: And you have how many there right now? []

JOHN WYVILL: We have 256 and we have three already scheduled for discharge in the next week or two, and then we are working with ILC, which is a... []

SENATOR LATHROP: What is ILC, John? []

JOHN WYVILL: Integrated Life Choices. It's a provider that we're looking for to establish a pilot program for at-risk clients--that's just a term that we use--working very closely with John McGee, the independent expert, to make sure that we have the appropriate transitions and safeguards in place. []

SENATOR LATHROP: Is this a new provider? []

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JOHN WYVILL: This is a provider I think has been around for about five or six years, I think.

SENATOR LATHROP: In Nebraska, John?

JOHN WYVILL: In Nebraska. And they spun off I think of DSN. []

SENATOR LATHROP: What's DSN?

JOHN WYVILL: Disability Services of Nebraska. I think that's Roger Stortenbecker's group. []

SENATOR LATHROP: This...what's it called, the group? []

JOHN WYVILL: ILC.

SENATOR LATHROP: ILC. Where are they located or...?

JOHN WYVILL: I believe in Lincoln.

SENATOR LATHROP: Do they have a facility? []

JOHN WYVILL: I think they have a large number of clients. I'm drawing a blank on it right now--kind of stressful. []

SENATOR LATHROP: Oh. (Laughter) I'm not trying to make this stressful, John. I'm just trying to understand...

JOHN WYVILL: I know, but...

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SENATOR LATHROP: ...because this is our last hearing and it's really my last chance to ask you these questions. The ILC, is that a community-based program?

JOHN WYVILL: That's a community-based provider. That's correct.

SENATOR LATHROP: Is it going to be an ICF/MR?

JOHN WYVILL: So tell me what...? Have you entered into a contract or you're discussing entering into negotiations?

JOHN WYVILL: We're in the process of amending a contract right now. We've been working very closely with them to take on, as a pilot program, several of our clients, and then when John McGee came on board, the independent expert, that was one of the first visits that he visited with, and offered some very positive suggestions as to what we need to do to address those issues for community placement. []

SENATOR LATHROP: When you called it a pilot program, can you describe this program? []

JOHN WYVILL: It's a pilot program that deals with what's classified at-risk. They may have some behavioral issues that, quote, the ordinary individual may have, and with this pilot program we're going to see if those individuals can be better served in the community because they have expressed a desire to be in the community. So we are looking for a rural residential setting for those clients. []

SENATOR LATHROP: Did you say a rural residential... []

JOHN WYVILL: A rural residential--out in the country. []

SENATOR LATHROP: Out in the country. So is it going to be an institution? []

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JOHN WYVILL: No. It's a community-based... []

SENATOR LATHROP: How many people are they going to take?

JOHN WYVILL: I don't have the number right off the top of my head. I would have to confer with Jodi Fenner and our staff.

SENATOR LATHROP: Okay. But you were...just...I'm not asking you to get it down to the like the person, but you're talking about moving 50 more people out by the end of the year? []

JOHN WYVILL: Not with them, no. []

SENATOR LATHROP: Okay. So how many of the 50 that you think you're going to move? []

JOHN WYVILL: I think it would be under 10, but I think once that happens that might have a snowball effect on some of the other providers. []

CHRIS PETERSON: Twelve.

JOHN WYVILL: Oh, 12. I'm sorry. []

SENATOR LATHROP: Okay. With the help of Chris Peterson, now we've got...the number is 12. Do you have 12 volunteers? []

JOHN WYVILL: I believe so. []

SENATOR LATHROP: Okay. Do you have a strategy for the balance? That would still

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leave 40 people that you want to try to integrate into a community setting. I guess...give me your thoughts or your strategy or your idea, because we have some concern, as a group, about the community-based programs. We heard some things about them not being well-regulated and not...they don't have the oversight. And so give us some comfort that if you move 50 people that it isn't a right-size move, but we are taking a chance with these lives as we move them to the community. []

JOHN WYVILL: Well, we are working on a couple different strategies as I mentioned before, that we are working with a matrix of 50, I think around 50 clients that we have identified for community placement. And we're working individually with those, and those developments can change daily based on the information we provide to the guardian and putting the right provider in or meeting those specific needs. In addition, we also, as part of the DOJ agreement and others, we have implemented a mentor program with a lady by the name of Joyce Werner who is our client advocate that is based in our Lincoln office, who is creating a structure of a mentor program reminiscent of an older program in the olden days with The ARC of Nebraska, that hooked up potential guardians of people who are wanting to be placed outside of the community with a person that's either successfully placed in a community or someone who is going to. And our next step is then to go back and talk with them, because as we have heard from the Department of Justice and our independent expert is that some of the barriers to the guardian opposition may be something very simple as getting the right people, the education of them of what is available to them, and also explain it by someone other than a, quote, state employee so they can have someone that has a, quote, no dog in the fight or it's not their job so they can get a realistic... []

SENATOR LATHROP: That was kind of a recommendation of Liberty, too, wasn't it, to have that a person that... []

JOHN WYVILL: I believe so, yes, and they've had tremendous experience and success outside the state, so that's what we're doing and we have established a small pilot

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program. And then we start going back...I think we're going to be identifying of those 92 that I mentioned to you and we're going to start going back to address, for example, the 20 that can be placed right away and then sit down with them on a case-by-case basis just to see it. Now there may be some that says BSDC is the best place on the face of this planet for our clients and for our loved ones and we may... []

SENATOR LATHROP: I was going to ask you, out of that 50 how many of them are willing or how many do you think you're going to have to have a hearing and get in front of an administrative law judge and... []

JOHN WYVILL: I think right now we're honoring the client choice of the 92 that we're looking at. The other 50 that we're working on has already in some form or fashion indicated consent, so we're working with them, but we want to make sure that we have the safeguards. And we should have, you know, realistic pictures. I mean, that can change daily in terms of... []

SENATOR LATHROP: Okay. I think I've ask you this. You've not seen a report from Expert McGee--Dr. McGee. []

JOHN WYVILL: No. []

SENATOR LATHROP: Okay, because he was supposed to come up with one or he had 90 days or a quarter, and that would have ended... []

JOHN WYVILL: Yes, he's supposed to give us one after the first quarter, and I think the agreement spells out how that's communicated, I think, but we haven't seen it or I haven't seen it. []

SENATOR LATHROP: Okay. He's just writing it at this point in time. []

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JOHN WYVILL: I would assume so. []

SENATOR LATHROP: Okay. Do you have any kind of a strategy for or do you have any intention of addressing, by delivering more services to more people, addressing the waiting list? []

JOHN WYVILL: In terms of that we are holding off on anything because we don't want to substitute or superimpose our judgment of this committee or the LR156 committee that's giving their recommendations by the end of the year. []

SENATOR LATHROP: You've made budget requests for Developmental Disability Services. []

JOHN WYVILL: That's correct. []

SENATOR LATHROP: Did it include any additional...requesting any additional monies for eliminating some people off of the waiting list? []

JOHN WYVILL: No, sir, it does not because of the reasons I mentioned. []

SENATOR LATHROP: Which is you're waiting for the LR156 committee to tell you how many people are on the list? []

JOHN WYVILL: I'm waiting for the recommendations of this committee and the LR156, and I didn't want to prejudge or presuppose the work of either one of the groups. []

SENATOR LATHROP: I think that's all I have, John. Let's see if anybody else has any additional questions. It doesn't look like it. []

JOHN WYVILL: Okay. Thank you for your time. []

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SENATOR LATHROP: As always, thank you for your candor and being here today.

CHRIS PETERSON: Good afternoon, senators. I'm Chris Peterson. I'm the CEO of the Nebraska Department of Health and Human Services. I'm glad to have the opportunity to come before you today. I know this is the last of your hearings so I welcome the opportunity to have this discussion with you and I'll try to answer all your questions that I can. []

SENATOR LATHROP: Senator Gay.

SENATOR GAY: Thanks, Chris. Chris, Ron was telling me earlier, I was really concerned about the numbers of the staff we've got to hire, okay. Then I'm listening to John Wyvill and he's saying, listen, if I can get these programs in place we're going to right-size our number possibly down to 200. If those all come and those are successful in a way that takes care of the safety and needs of those clients and not push them out the door--and I know you won't but--so those numbers that Ron was throwing out will reduce dramatically then. We won't have 160 different positions that we need at that point. Am I understanding this correctly? []

CHRIS PETERSON: Yes. And I think the way to clarify it is the numbers that Ron is looking at, we're building on top of what's already there. We might get to the point when we get down to 200 there would be some attrition that we wouldn't fill if we continue to have the vacancies. But right now, where we're at is we're maintaining the same level of staffing we had with 300 people but we're taking the census down, because we want to get to the point where--I think our ratio has gone from 1.35 down to 1.2 so we're making some progress on that. It's not easy to find people, obviously, and I appreciate what Senator Lathrop said about whether it's Beatrice or whatever. But it's not just the salary. There are a variety of other issues. It's a tough job; mentoring helps for that. We're looking at the recruitment and retention that the Legislature authorized has helped for

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that. I think the fact that we've consolidated some of the buildings and we've put more staff on the units has helped. All of those little pieces, as well as the training, as well as the interest in the Legislature, and also just pride that we have in people that have worked there wanting to make it right, we are slowly chipping away at that. We're not there yet. We'll get there but it will take awhile. []

SENATOR GAY: Um-hum. So, okay, it's late Friday. You're telling me then if we get down to 200 residents there that I will or I will not need all these employees that we were talking about earlier with Ron. []

CHRIS PETERSON: At 200 we will not need all of those employees that are there. []

SENATOR GAY: Okay. How many would we need do you think? Just ballpark. You don't need to be...a third of those? I mean, because we had...I mean...and I'm more interested in...that's a lot of direct line shift supervisors. The speech pathologists and some of these harder...you know, that's problems statewide not just Beatrice. []

CHRIS PETERSON: Yes. []

SENATOR GAY: But some of the direct line people will go down tremendously then if we right-size to 200 residents. []

CHRIS PETERSON: Senator, I wouldn't say...let me put it a different way. Let me just start all over. Yes, but it won't be because they're laid off. It will probably be because of attrition with the turnover that we have. What I'd like to get for you is... []

SENATOR GAY: Okay, so we're accounting for turnover then because staff... []

CHRIS PETERSON: We will have...we're going to have continual turnover. We will do that. []

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SENATOR GAY: Okay. So that's why the numbers are so high then.

CHRIS PETERSON: Sure. In addition, we've...

SENATOR GAY: You're anticipating turnover, getting...

CHRIS PETERSON: We want to be...yeah, we're forward filling. I mean we call it. We're forward filling. We're assuming that we're losing people off the back end and so we're moving forward, bringing them in and training them at the same time. It takes awhile to be completely trained as a DT tech.

SENATOR GAY: Yes. How long? []

CHRIS PETERSON: I think six months. Ron would have a better idea of that but it's...you do up-front training for a short period of time, less than a week, but then it's over six months. []

SENATOR GAY: Okay. So we're stopping the flow out, hopefully, with some of the retention things that have been done... []

CHRIS PETERSON: Absolutely. []

SENATOR GAY: ...the confidence in what they're doing, and they're all good employees. So what I'm considering maybe is not such a crisis situation as I was originally understanding it, or I was getting very worried. You're being proactive to cover those positions. . []

CHRIS PETERSON: Yes. Yes, we are. []

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SENATOR GAY: Okay. And then real quick--it doesn't have to be quick I guess but --where is your vision of helping John, the concern is and Senator Lathrop discussed this, we don't want to just, for our convenience, right-size. We want to right-size for the right reasons--for quality of life issues for those residents--for the right reasons. But I guess down the road is the how do we make sure that these people are secure, they're safe, and that they're going to get a better quality of life in the community? How can you assure us and then we could go assure our colleagues that (a) we're doing this and ongoing monitoring of those programs? []

CHRIS PETERSON: Two things. I think first is the assurance that we won't find ourselves in the same situation that we were at with BSDC two or three or four years down the road, and then the second is that you're asking for assurance of the oversight when people move out into a community program. And I think that both of those are issues that are going to require a lot of collaboration. We have good providers out in the community. We actually have service coordinators that are staff that go out and work. Probably our best eyes and ears many times are the relatives and guardians that are there. We need to have a coordinated way to do that. Whether it's through a partners' council that formulates some way of regular checks, whether it's working with...we're going to be moving people. For the first time, we have the service coordinators and BSDC under the same core function, the Developmental Disabilities division. We're going to be able to assign with the new rules and regs we're going to have some openings in some of our positions as well as Public Health, so I think with the efficiencies that we can achieve we'll be able to find some people to take care of looking at going out in the field, doing those spot-checks, making sure that they are getting the service. Contract oversight is an issue that we're going to try to deal with across the whole system, and how we do that, whether we hire someone to do it, whether we use our own staff, and through efficiencies that we don't need them for one thing, put them over there, but we'll have to manage that. So I don't have it directly exactly how we're going to do it but we will make sure that people are monitored in the community and we'll do with the assistance of the providers, I'm sure. They've always been willing,

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collaborative on that. And in terms of how do we make sure BSDC doesn't happen again, one of the things that I wanted to touch on just quickly was something that Ron brought up, as well as John. When the original reorganization happened I think you've been at the hearings where they've said it stopped before it went all the way through because you ended up with three separate agencies instead of the one. And so through this Legislature's work, with the administration, we now have the structure that the original "reorg" was supposed to have. I think that's essential to remember that in terms of accountability, because there were times when the CEO reported to a director, reported to an administrator, reported to Behavioral Health. And I think by passing the reorganization bill and putting the core responsibilities of DD in one place under one director, with both the service coordination and BSDC, for the first time you're really combining the two. Back in the '90s when people were saying we're the best we ever were, that was really when the Community Developmental Disabilities Act was passed was in 1991, and the focus then was in the community. Beatrice was held separate from that. There was no real connection made and that continued throughout. They have to work hand in hand. Beatrice should be seen as the place where the expertise is at. When we get our providers and our people out into the field I would like to see Beatrice as the facility that takes care of the people that have the toughest challenges. It's also where people who are in the community, if they need to come back and have more work with the experts that are better there, they'll do that, but for the most part people will be served in the community with adequate supports there, monitored both by providers and the state with the best practices and their safety always first in mind. []

SENATOR GAY: And the monitoring, how long do you think that vision takes? []

CHRIS PETERSON: Monitoring has got to start right away, Senator, so as we're putting them out there now, we're going to have to increase the oversight that we have of them.
[]

SENATOR GAY: And you're developing that now but you can't speak... []

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CHRIS PETERSON: Right. []

SENATOR GAY: ...right now exactly.

CHRIS PETERSON: No.

SENATOR GAY: That will be continued to be worked on.

CHRIS PETERSON: Yes.

SENATOR GAY: Thank you.

SENATOR LATHROP: I do have a few questions, Chris, and thanks for being here. I know this isn't easy for your office and your agency, the whole Beatrice Development and the problems, but I've got to ask a few questions because today is kind of the first I learned that we still hope to have 50 people moved from Beatrice by the end of the year. And that gives us two and a half months, right, to move 50 people. That's a significant number, a significant part of the population, and it makes me recall the comments of Liberty when they said I understand you want to move 100 people out; that's really aggressive and you need to make sure you've got everything put together and all your ducks in a row before you do that, and you need a service coordinator to make that happen. So I've got a question for you that maybe starts with these 12 folks that are moving from...you'd like...these are behavioral folks, so in the spectrum of people with developmental disabilities these people have some cognitive difficulties but they also have behavioral difficulties. Is that right? []

CHRIS PETERSON: Yes.

SENATOR LATHROP: That's the population of people that make up the 12 that you

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want to move to...and is it a farm?

CHRIS PETERSON: You know, Senator, they do have a building picked out. I'm not sure if it's considered a farm. It's a house.

SENATOR LATHROP: I think you said a rural setting. Is it out in the country?

CHRIS PETERSON: Yes.

SENATOR LATHROP: Is it...because Lincoln isn't on the farm so it must be out in the rural area out on a farm somewhere, is that right? []

CHRIS PETERSON: What I can tell you from what I know--and Jodi Fenner has had the specific discussions with them. In fact, I think it's been decided today how to finalize that. It's in a rural setting--it's not in a city--with the understanding that it will provide services on site for people that have some behavioral health needs that they had from a behavioral health plan when they were at BSDC.

SENATOR LATHROP: Okay. Now we're doing this so that the number...the employees...the staff that we have is going to work for the number of people you want to get down to. That's sort of the strategy.

CHRIS PETERSON: You know actually, Senator, that's probably one of the reasons, one of the benefits that we're looking at. I shouldn't say reason. When CMS came through and when the Department of Justice came through, it was very clear that they felt there should be people served in the community. And so ultimately the people that we're putting out into the community, moving into community transitions, it's with the understanding that they will be in a less structured atmosphere. It's a deinstitutionalization. That's always been a goal.

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SENATOR LATHROP: And what I want to express to you is I don't have any trouble with that philosophy. The idea that somebody that wants to be in the community can get there through community services sounds like a...who can argue with that? Here's my concern. []

CHRIS PETERSON: Okay []

SENATOR LATHROP: You take somebody from Beatrice, and the fact that it's an institution means it's separated from the community, and we're now going to put them on a farm, and they're not exactly going to be able to walk to the barbershop from the farm, right?

CHRIS PETERSON: No.

SENATOR LATHROP: And so it's not really putting them in the community in the sense that they can go shop, they can walk and they can go do things and interact with the rest of the community.

CHRIS PETERSON: They will, I'm sure, as part of their individualized plan. They will be transported or drive or whatever, but they'll have sufficient staff with them to allow them to do that. []

SENATOR LATHROP: Okay. This whole developmental disability thing is new to me so I'm asking some questions and I'm not...it's because I really don't understand all of it. And it seems kind of basic that if they're at Beatrice and CMS says...and the Department of Justice and the agreement we reached with them says you'll have psychiatrists, you'll have neurologists, you need speech therapists, occupational therapists; you name it, the specialists are all going to be there for them. If we move somebody from Beatrice to the community, have you made sure that these 12 people will be evaluated by psychologists, psychiatrists, medical doctors, good dentists, and all

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the therapies just as they would if they had remained at Beatrice? []

CHRIS PETERSON: Yes. []

SENATOR LATHROP: How are we able to do that if we can't hire the staff at Beatrice?
[]

CHRIS PETERSON: You have the ability to take people as they do now. I mean they are not getting people who are in the communities now that are developmentally disabled are coming to Beatrice to get their services there. They're like you and I. They can go to anyplace. I mean, they're all Medicaid-eligible so their bills are all paid through the state and so they would find a provider like that. I am assuming that we would be working closely with the providers to ensure that, because that's part of the responsibility of the provider to ensure that that person has those services available to them. []

SENATOR LATHROP: What...if...I'm kind of struggling with this and it is late and I know everybody is getting tired but I'm going to ask these question anyway. []

CHRIS PETERSON: Sure. []

SENATOR LATHROP: You have somebody that's at Beatrice, and CMS is looking over your should and they're saying and the Department of Justice is saying, this, this and this and this have to be done, and I really don't have a sense that if you take somebody from Beatrice where there are people looking over your shoulder and take them to a farm or take them to a house or take them even to an ENCOR which is a program I've got a lot of respect for, that anybody is going to say, you know what, it doesn't look like this guy has seen a psychiatrist or he hasn't seen a neurologist. Who's making sure that once they leave Beatrice that the people, these clients, are actually...somebody is assessing who they need to see, that that's getting done? And if it isn't, how do we find

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out that it isn't?

CHRIS PETERSON: A couple of things.

SENATOR LATHROP: Are we just going to wait for the guardian or the parent to go, my daughter hasn't seen a doctor in two years?

CHRIS PETERSON: No. First of all, BSDC will be tracking them, I believe, up through 90 days to make sure that the placement is working, that everybody is happy. You're aware that all of these placements are voluntary on both sides. The provider...it's voluntary on the provider's side; it's voluntary on the client's side, so they can change at any time. The second thing is they still have a service coordinator which is, in essence, case management. That's the person. And each person has case management service coordination. That's actually one thing that anybody that qualifies for developmental disability services gets. That person is the monitor to make sure that they're getting that. They have a team that is to be evaluating them. And so I would say, Senator, the pieces are in place. What we have to do is monitor to make sure that they're done, and we do that the same way we did when we had caseworkers with our child protection services. We have to have the supervisors check to see how many times the cases are being monitored, once a month, how often do you visit them. We set benchmarks and then we hold people accountable to that. []

SENATOR LATHROP: Is that just in the first 90 days after they leave Beatrice? []

CHRIS PETERSON: Um-hum.

SENATOR LATHROP: Because I'm not getting the sense from our meetings or our hearings last month that somebody comes by once a month and checks up on the guy who's in the community-based residential setting. Are you telling me they do?

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CHRIS PETERSON: I'm going to just...I'm going to have to let me get back to you on that. But for the most part I do believe that there is a 30-day to 60-day check. Yeah, I think so. []

SENATOR LATHROP: A 30 to 60-day check from... []

CHRIS PETERSON: A service coordinator.

SENATOR LATHROP: That's a window of time that they check up on them after they leave Beatrice, or you think a service coordinator checks up on everybody, and John and Jodi and even Lawyer York is shaking his head yes.

CHRIS PETERSON: Would it be inappropriate if I turned around and got clarification for those two questions?

SENATOR LATHROP: I think it would be helpful.

CHRIS PETERSON: Great. Ron?

RON STEGEMANN: For BSDC a social worker (inaudible) checked every 30 days. (Inaudible) minimum of (inaudible). []

CHRIS PETERSON: So the social worker will do a check for the 90 days after they go out to their community placement.

SENATOR LATHROP: That I kind of understood.

CHRIS PETERSON: Okay.

_____: (Inaudible).

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_____ : After that the service coordination does spot-checks for as long as that person (inaudible) services. Part of the DOJ agreement with people leaving BSDC is they have to have a limited number of individuals assigned to the service coordinator for those individuals. And John McGee, the independent expert, actually has jurisdiction over those (inaudible).

SENATOR LATHROP: I got that much, and that was sort of the window after they leave Beatrice there is some coverage, there's some checking up on them, there's some follow-up, and there may be a legion of people following those folks, but after 90 days then we're left with...is that where we fall into the oversight or lack of oversight that we heard, which is, well, we check up on those providers once every four or five years?

CHRIS PETERSON: I think those were the people that were...the licensure people, and they had to do an annual recertification. []

SENATOR LATHROP: Maybe that's the question. Is there somebody besides the licensure people?

CHRIS PETERSON: Yes. The service coordination people.

SENATOR LATHROP: And they do what? Spot-checks? []

CHRIS PETERSON: Yes.

SENATOR LATHROP: And do you know the frequency of the spot-checks?

CHRIS PETERSON: I don't, Senator, but I will get back to you on that. []

SENATOR LATHROP: Okay. That would be helpful. Do you think that the

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community-based providers are ready for the 50 people that you want to move from Beatrice?

CHRIS PETERSON: Our goal is set for 50 people. If we don't meet that, we'll continue to work towards that goal. We're just not going to...we're not going to not continue to work towards our benchmark. Part of the reason that people are not going out into the community so quickly is...there's several reasons. First of all, like you said, some of the easier ones to be placed, are placed. The next easier ones, maybe those have a guardian who is opposed to that, and we're certainly not going to change that. In addition though, the special monitor has asked us to take a little more time and make sure that some of these placements, there's more overnight stays, there's more visits during the day so that we're more comfortable with that happening, and I don't see any drawback to that. We also run into a couple of issues where people need adaptive things done for them, wheelchair ramps, accessibility, like that. So through one of the waivers that we have, we're in the process of making those connection to build the ramps, build the ADA accessibility pieces. And then the last one is similar to the ILC. We have some services that just aren't there so that we have to work with the provider to bring those up, and that's probably why the first 50 that we worked with, they were easier to set up. These are a little more of a challenge. It's going to take a little bit longer to do that but the goal is still the same. []

SENATOR LATHROP: Do you have...to get to...to place the 100 people that you wanted to place, do you have to have anybody who isn't agreeable to it get involved in a hearing over whether it's in their best interests, whether you disagree with the guardian?

CHRIS PETERSON: Part of what we've seen with the placements that have been out there, people are coming back to visit BSDC and saying I'm good, I'm doing all right. I think that we will eventually, as it becomes more prevalent or more well-known, we'll have some guardians that will be interested in taking a look at it. At this point, no, we don't want to force anybody to do that. []

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SENATOR LATHROP: You have no plan or expectation or long-range goal that will involve trying to move people from Beatrice who are unwilling?

CHRIS PETERSON: No, we do not.

SENATOR LATHROP: Do you have...I asked John this and I think I'll just ask you, to give you an opportunity to address it if you care to or if you have anything to say that John hasn't, and that's the waiting list. We've heard testimony yesterday and when we took up the waiting list previously that essentially the waiting list is static unless you become a priority one, and you become a priority one by essentially having either both your parents die or whoever is taking care of you leave you somewhere. Do you have any...you, director of Health and Human Services, do you have any strategy for or plan to reduce the waiting list for DD services?

CHRIS PETERSON: Senator...and I think John answered it the way I would. There are two pieces going on right now. One is LR156 which is going to come forward with recommendations for the waiting list, and then second is what we saw this commission also doing. And so, no, we did not put anything into our budget specifically related to the waiting list.

SENATOR LATHROP: I was...somewhere along the way somebody said, well, you know, they had a statute that said you have to get the waiting list down to zero at one point, and we moved it and we moved it and I never run into it, but I found it.

CHRIS PETERSON: Yeah, we moved it. It was our recommendation to do that because the last...

SENATOR LATHROP: I found it--83-1202.01. It's an appropriations statute that says it's the intent of the Legislature to pursue full funding of community-based developmental

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disability programs in a reasonable time frame and the Legislature commits itself to a goal of providing services to all eligible persons by July 1, 2010. Are we...anything in the works to make that happen? Are you going to...

CHRIS PETERSON: No, sir, not from the department.

SENATOR LATHROP: ...tell the Legislature how much money you need to make that happen?

CHRIS PETERSON: I think we have--\$80 million. []

SENATOR LATHROP: Are you requesting that... []

CHRIS PETERSON: No, I'm not.

SENATOR LATHROP: ...or have you made that request for that appropriation?

CHRIS PETERSON: No.

SENATOR LATHROP: I mean, I'm just trying to find out because this is our last opportunity, Chris, and...

CHRIS PETERSON: Senator, I think it's fairly clear. We told you how much the waiting list is going to cost. We also know that DD services are not entitlements. You've seen what happens with Medicaid. We're constantly trying to control the growth of that. We do have a system in place that people, if they are a priority one, they will get the services. All of the new, young adults that come on at 21, they're built into the base, so we're bringing it in forward from the back end.

SENATOR LATHROP: And they get day services.

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CHRIS PETERSON: Yes, they do. (Recorder malfunction--some testimony lost.)
...contract. Take the people out to get it, and we're working with Liberty and Guardian to try to do that, and we've filled I believe three positions, and we have one close to fill. In terms of the DD staff, that is set by...as Ron explained, that is set by the CIR ruling and the negotiations that we do with DAS. Now I took it to mean that he felt that he should be paid more. That was purely my...the way I read it.

SENATOR LATHROP: Who is he?

CHRIS PETERSON: Ron that we were talking about needing more money.

SENATOR LATHROP: Okay. And they being the techs.

CHRIS PETERSON: They being the DD techs. Yes. That being an issue, that is really outside of our purview. That's going to be a negotiated settlement. What we're working on, it's negotiated between Labor and DAS and they start in...

SENATOR LATHROP: Yeah, but I thought I saw that contract got tossed around the floor when this came up the last time and there is a provision right in there that said you're free to pay whatever you have to pay to hire the next guy. There is not a prohibition in the union contract that prevents you from paying additional dollars. You just can't pay less.

CHRIS PETERSON: Absolutely there's not. There's no prohibition at all on any of that.

SENATOR LATHROP: Okay.

CHRIS PETERSON: And what I would say is I think that with the latest ruling that the wage is comparable to the area market. I think it's other things than just the wage and I

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think we've seen that in the last two to three months... []

SENATOR LATHROP: Wages certainly aren't the only thing. We're hearing that consistently.

CHRIS PETERSON: Yes. People that work there are very special, and if they feel appreciated and if they feel that they're going to get a weekend off or they feel they're not going to have to miss some special thing because of a mandatory overtime, those are the things we can fix and we're trying to fix. One of the ways we're doing that is working with the union on the interest-based bargaining, and I think we just finished up last week. And everything that we had, including our time and attendance policy, we came to agreement on. Some of those we'll be implementing, like the staff rolling over in terms of full rotation. There's ways to get this done without just putting the money in it, I believe, and that's why I feel that we have the resources to do that with the two and a half for both years.

SENATOR LATHROP: What's the two and a half buy you? Is that...?

CHRIS PETERSON: I don't have the list.

SENATOR LATHROP: In other words, if you we took last year's budget or the last two year's worth of budgets--and now I'm wandering into John's area which is appropriations because I'm certainly not an expert on the appropriations process--but if we took the Beatrice budget for the last two years, are you asking for \$2.5 million more a year from that base?

CHRIS PETERSON: I believe the base rises itself based upon the budget instructions on the facility costs. That's part of your budget instructions when you do it. There's a formula that builds in to each of the 24-hour facilities, and it takes care of maintenance and depreciation and all those things.

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SENATOR LATHROP: So in addition to that you're asking for \$2.5 million a year.

CHRIS PETERSON: Yes. Two and a half on that.

SENATOR LATHROP: And that is not for increasing the techs but it is for hiring the people other than the techs--the professional staff.

CHRIS PETERSON: No, the new 66 supervisors are in that \$2.5 million, too. The techs will already be funded.

SENATOR LATHROP: So you're hire 66 supervisors.

CHRIS PETERSON: The techs will already be funded because they're built into the base.

SENATOR LATHROP: Okay. I'm going to have to trust John will figure that out in Appropriations. But you think you will hire all the people you need to hire so that we're not in the box we're in with CMS.

CHRIS PETERSON: We are doing everything that I believe we can do to do that, but beyond just the hiring--just the hiring--we have to find other ways to also get at the points CMS have, which is active treatment as well as client protection. We can hire all the people in the world, and if the attitude and the culture and the training is not changed, we're just going to continue to make the same mistakes over and over and over again. So, yes, we've put in the money so that we can hire these new staff, but in addition to that we have to get to the training aspect which goes back to what Senator Harms was talking about. Ethics, cultural changes, all types of different groups are out there to come in and that's one of the proposals I have, looking at not only to bring in a group like that but also to maintain the recruitment and retention on past when it runs

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out with the Legislature with those federal draw-down dollars that we will have. In order to continue to recruit, I've got a proposal in to Dennis Baack from the community college that he's going to get back to me so that we can grow our own, starting with RNs, LPNs, and put that together. We actually have the unemployed people, Employment First, so we're looking at putting a subsidized program. We have the unemployed people; we have the facilities that need them. So I've asked the staff to put together programs that we will link upwards of 10 people at each facility with our own Employment First program in our facilities. So there are other things going on than just the money in order to try to get to where CMS is at--where they need us to be, I should say.

SENATOR LATHROP: Okay. Senator Wallman.

SENATOR WALLMAN: Thank you, Senator Lathrop. Thank you, Chris, for being here. Say that Senator Stuthman and I have an abandoned farm place and we're going to set up...we want two or three challenged young adults. What would we have to do to get a license and how easy would that be or how hard?

CHRIS PETERSON: It's complicated. It's complicated. You have to do a certification licensure process through Public Health as well as through the Division of Developmental Disabilities. And actually, the packet to apply, you have to meet certain standards, qualifications, accreditation, the staffing, the training, things like that. So, yes, you'd have to do some hoop-jumping.

SENATOR WALLMAN: And what would that cost us?

CHRIS PETERSON: Oh, the cost for a license? That I don't know.

SENATOR WALLMAN: Okay.

CHRIS PETERSON: But no, Senator, you can't just go open up a farmhouse and put

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people out there.

SENATOR WALLMAN: Thank you.

CHRIS PETERSON: And probably it was an inadvertent use of the term "farm" but I believe that's what they're looking at. It's in a rural setting.

SENATOR LATHROP: Senator Gay.

SENATOR GAY: Chris, you brought up a fact just there in the end or kind of an idea of what you're working on. Senator Harms and I have been working on the work participation rates and actually we're going to go try to talk to the community colleges, as well, to find opportunities for work study. We would like to talk to you, just that you mentioned that and I'm just saying this because I know we're going to be talking next week.

CHRIS PETERSON: Absolutely.

SENATOR GAY: But I think that's a great opportunity where we need to plan for the future. And if you are talking about community-based services, we train for those shortage areas we have in the medical community, and this would be with DD. But if we can get them trained, this is a great idea...or we want to work with you on that because I think that's going right to where we were looking, too.

CHRIS PETERSON: Absolutely.

SENATOR GAY: So that's something that's marked on our to-do list, and thank you.

CHRIS PETERSON: Okay. You bet.

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SENATOR LATHROP: Are you sure, John? I think that's it, Chris. Thanks again for coming down.

CHRIS PETERSON: Thank you, Senator.

SENATOR LATHROP: We appreciate the information.

CHRIS PETERSON: You bet. Thank you

SENATOR LATHROP: Anyone else here prepared to testify or have we seen the last of our witnesses? That looks like it's it. I want to thank the folks that have testified today. They have...you may have seen them testify. They have testified at probably two or three hearings apiece at least. John, maybe more than that. They have been responsive when we've asked for material, and we've had a lot of conversations with them that have been beyond here, and I appreciate the time they've taken to educate me and to provide information to the commission. So anyway thank you all for your participation and for your interest in the subject matter, and I guess now we're left to write a report. So thank you.